SHAPES

Smart and **H**ealthy **A**geing through **P**eople **E**ngaging in supportive **S**ystems

D2.1 – Understanding Older People: Lives, Communities and Contexts

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Table 1 Revision History

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0.1	26/08/2021	NUIM T2.1 Team	Establishing table of contents and inclusion of relevant information in each section
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8. Legacies and Future Worlds	Katja Seidel (NUIM) // John Foley (NUIM), David Prendergast (NUIM)
9. Conclusion	Katja Seidel (NUIM) // David Prendergast (NUIM), A. Jamie Saris (NUIM)
10. Ethical Requirement Check	Katja Seidel (NUIM) // A. Jamie Saris (NUIM)

Table of Acronyms and Abbreviations

Table 3 Acronyms and Abbreviations

Acronym	Full Term
COPD	Chronic obstructive pulmonary disease
EU	European Union
GDP	Gross Domestic Product
GDR	German Democratic Republic
GP	General Practitioner
HCP	Healthcare Provider
HIA	Healthcare Associated Infection
MDK	Medizinische Dienste der Krankenversicherung
MRI	Magnetic Resonance Imaging
ObK	Oberbergischer Kreis (regional district in Germany)
OECD	Organisation for Economic Cooperation and Development
UNECE	United Nations Economic Commission for Europe

Keywords

Lifeworlds, Older Adults, Learning, Digitalisation, Technology, Mobility, Home, Labour, Finances, Informal Care, Formal Care, Legacies, Bereavement, Age and Ageism, Agency, Empowerment

- Chapter 1: Recruitment, Methods, Agency, Lifeworld, Europe, Ageing, Ethics, Participation, Practice, Purpose, Process

- Chapter 2: Daily Life, Adult Education, Digital Upskilling, Family, Friends, Routines, Hobbies, Learning, Exercising, Purpose

- Chapter 3: Mobility, Falls, Transport, Driving, Accessibility, Stairs, Wheelchair, Walking, Home, Public Space

- Chapter 4: Employment, Work, Volunteering, Chores, Division of Labour, Housework, Shopping, Participation

- Chapter 5: Gender, Pensions, Home Ownership, Rent, Budget Management, Heating, Power of Attorney, Sandwich Generation, Affordability, Decision Making

- Chapter 6: Dementia, Caregiving, Care work, Community Care, Respite Care, Peer Support, Gender, Independence and Interdependence

- Chapter 7: Care, Hospitals, Nursing Homes, Obesity, Communication in Health Care, Empowerment, Patient-Centredness, Dependency Steps

- Chapter 8: Memories, Technologies, Change, Generations, Bereavement, Inheritance, End of Life, Advice, Agency, Control, the Future

- Conclusion: Identity, Old Age, Ageism, Participation

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Executive Summary

Deliverable 2.1 (Understanding Older People: Lives, Communities and Contexts) of the SHAPES project presents the findings of 20 months of ethnographic research in eight countries across Europe. It describes the lifeworlds of older adults living independently, their challenges, motivations, hopes and worries. Data used for this report consist of 378 hours of recorded, transcribed, and translated interviews with 94 individuals between the age of 61 and 93 in 10 SHAPES pilot and reference sites (Czechia, Finland, 2x Germany, Greece, Italy, Northern Ireland, 2x Portugal, Spain). All personal data used in this report has been anonymised and all research participants are given pseudonyms to protect their privacy.

The seven chapters and conclusion of this report present patterns and key themes of older adults' cultural, social, political, and economic ways of living through descriptions, ideas and critiques presented by older people themselves, and through our own analysis.

Chapter 1 (Introduction) presents the rationale and purpose of the report, the core aims and outputs, a methodology section, and a discussion of core concepts such as lifeworld, agency, and ageing.

Chapter 2 (Social Worlds – Living, Learning & Liaising) engages with how people perceive relationships, daily activities and hobbies, learning and digital worlds and highlights the importance of agency and choice in the later life course.

Chapter 3 (Moving through the World) explores the experiences of older adults moving within and outside their homes, the barriers encountered, and what established and creative coping strategies are employed within domestic environments and navigating public spaces and transport systems.

Chapter 4 (Working Worlds) discusses three main areas of labour (managing domestic life and family support, volunteering, and paid work) and highlights older adults' contributions to and participation in society and the meaning and purpose of these diverse forms of labour in the later life course.

Chapter 5 (Financial Worlds – Spending & Affording) addresses challenges with income and material (in)securities, management of finances in the later life course and the importance of engaging with gendered dimensions of poverty due to unequal opportunities and pension schemes as well as the tough choices some older adults have to make.

Chapter 6 (Informal Care – Providing Care) explores caregiving practices of older adults, how senior citizens participate in and facilitate care practices in the family and society and how their choices and contributions are key to maintaining care structures in Europe.

Chapter 7 (Formal Care – Receiving Care) explores the experiences of older adults accessing and navigating 'formal care' through hospitals, GP practices, and nursing homes. We also discuss the gaps in service and issues of communication, agency, trust, and empowerment.

Chapter 8 (Legacies and the Future) engages with the meaning of life and death (including how technologies can facilitate this) and the changes faced in moments of bereavement as well as the importance of memories, leaving a legacy, and providing advice for the next generations.

Chapter 9 (Conclusions) provides a discussion on how older adults perceive age and ageism and a summary of the key themes explored in this report.

The report demonstrates the interconnectedness of elements and experiences in the lifeworlds of older people and the necessity for those who would intervene in their lives to understand and appreciate such connections. Attention to the frictions between older adults' diverse self-perceptions on age and outside impositions (including ageism) reinforce the findings that run through this report.

There were four principles that emerged from our engagement with these older people. These are: Providing older adults with the capability for choice (participation), creating an awareness for and engagement with change in all stages of life (process), recognising and enabling the active contributions and labour of older adults (practices), and proving the opportunity to live a meaningful life according to their own judgments (purpose).

D2.1 explores awareness of the hopes, fears, and recommendations provided by "older people", who are too often seen as a burden, a potential resource, or objects to be managed, rather than subjects to be engaged. It is only through such reformulations that we can improve the ways through which services and solutions are designed, developed, and delivered to this population.

INTRODUCTION
Chapter 1

Chapter keywords: Recruitment, Methods, Agency, Lifeworld, Europe, Ageing, Ethics, Participation, Practice, Purpose, Process

1 Introduction

WP2 of SHAPES (Understanding the Lifeworld of Ageing individuals and Improving Smart and Healthy Living) creates a body of knowledge on how ageing populations live, including empowerment models for healthy living, care pathways, age-friendly environments, and social inclusion. T2.1 of WP2 was tasked with researching the "Lifeworlds of Older People in Europe". The original research plan called for interviewing 10 community dwelling older adults in seven SHAPES pilot sites, each interview occurring over the course of two half-days of interaction. We had scheduled to begin this work in March of 2020. Clearly, the world then changed. The coronavirus pandemic made in-person interactions with older people both dangerous and unethical. Consequently, we radically reformulated our research methodology, creating an extensive online research toolkit and working through online video calls or over the phone.

The new approach required multiple online/remote interactions with each participant over the course of several weeks. Sessions lasted a minimum of one hour, with most being much longer. Such methodological changes from direct to online or analogue phone interviewing made it possible to significantly expand our research in two ways: Firstly, it allowed us to carry out interviews with each participant longitudinally over several weeks or months. Secondly, we were able to increase the number and range of participants in our cohort, through the addition of fieldsites in Finland, Czechia, and Italy to our list of pilot sites in Greece, Northern Ireland, Spain, two sites in Germany and two sites in Portugal. We worked in collaboration with consortium researchers embedded in SHAPES pilot and reference sites, training our team in the use of the T2.1 toolkit and online qualitative interviewing. Thus, in the end, we were able to talk extensively to 94 older people in 90 households, representing an increase of about a third in terms of sample size of the original proposal, and crucially including five older adults living with deafblindness.

This report provides a window on the lives of older people across Europe, their care networks and their articulations to formal and informal health and social care sectors. to inform the work in the SHAPES Pilot Sites and across the rest of the SHAPES ecology.

1.1 Rationale and purpose of the deliverable

This report investigates the lifeworlds of community-dwelling older adults across Europe. It is part of a large EU Horizon 2020 Action Research aimed at developing a Digital Platform and Ecosystem to make available technological solutions and services that address various issues that an ageing population encounters. In this work, we

represent the emic or insider perspectives of older adults on phenomena of interest in the SHAPES ecology to support policymakers, clinicians, and designers in the nuanced development of technologies and services that account for the diversity of ageing populations. To do so, we approached each older adult as an expert in their own lives – not the only one, to be sure – and acknowledged that their knowledge of their own person, perception, and environment is key to the success or failure of any social, technological, or health care intervention aiming at improving independent, smart, and healthy living.

The research and this report were informed by ongoing discussions amongst the research team around four foci in the work itself that then emerged as core concepts underlying the interpretation of our findings and principles of organisation in the writing of the report: (1) Practices – especially social practices, (2) Participation – specifically, the dialectic between alienation and a sense of control, (3) Process – the idea that any interaction is only a snapshot of what are in fact flows of social life, and that even stability is situated within these flows, and (4) Purpose – in the sense of meaning and motivation that we observed in, and how they were articulated by, older people.

This work then is much more than mere raw material for design personas and use-cases. Instead, we have tried to portray the real lives out of which such abstractions are developed. To this extent, we stress the qualities of these worlds, above and beyond the specifics that we describe, especially how any lifeworld appears organised from its inside and that the connections made by its inhabitants have to be taken seriously as a first step to assisting someone within it. Finally, it is important to stress that this report is a first analysis of an incredibly rich data set, and that it is written for the purpose of surfacing needs and opportunities of older adults resulting in insights relevant to the work done in the rest of the SHAPES ecology.

Lifeworld

Lifeworld is a term used broadly in Phenomenology, Anthropology, and some parts of other Social Sciences, although it may be less familiar for many other readers. Located in the work of Husserl (1970), and developed throughout the 20th Century in the work of Schütz (1945) and Hallowell (1960), the concept connects a wide variety of person-centered investigations in the Social Sciences. For the purposes of this work, we define lifeworld as the immediate experiences, activities, and contacts that make up the experiential world in an individual's life. It is the "given", common-sense world of subjects beyond – but also including – the physical (natural and built) environments in which humans exist. To this extent, it is not merely an idiosyncratic "viewpoint", but also a manifestation of collective meanings and ways of being in the world. As part of this meaningful world, humans experience other beings in three broad categories – intimates, consociates, and strangers. These are not fixed categories – not all family members are necessarily intimates, for example, and strangers can become intimates over time. At the same time, non-human beings, such as pets, can sometimes exist

as a special class of intimates. For the most part, we have explored these worlds from the perspective of intimates, but also moving out from those in home to the neighbourhood, local communities, or subjects who are more in the category of "stranger" in the broader world.

From this perspective, we use various themes to flesh out these lifeworlds. It should be noted, however, that these are viewpoints on what is experienced in these lives as interconnected phenomena even if they are not necessarily recognised as such by those with an external perspective. "Financial concerns", for example, can spiral into feelings of anxiety and lack of self-worth that can get read as "depression" from another (say professional healthcare provider) perspective on this same lifeworld, potentially mobilising various formal care interventions. Similarly, barriers to mobility can make a range of other facets of the lifeworld significantly more challenging, requiring, perhaps, extra interventions.

Agency

A critical theme in nearly all the facets we discuss is the balance between alienation and a sense of control (what we call participation above). We call this desire to exercise some choice within a specific environment, "agency". On one side, it is expressed as a desire to both share in decisions and to have a share of the control of a situation. On the other, it is the perception of someone as an agent in his/her environment. Viewed that way, older people resemble most other people from across the life cycle, insofar as they want to feel that they share in the decisions that directly affect them, and they want a share in the control of their own lives. When this sense of meaningful participation or the capacity of individuals to act independently to make at least some of their own choices is absent or severely limited, it is experienced as a significant burden.

Ageing

While this is a study of the lifeworlds of older people in Europe, we confronted the irony that many of our informants do not self-identify with the category of "old". They are not alone in this interrogation of such a seemingly fundamental concept. Cross-cultural work has shown up the peculiarities of a sharp separation of the "old" as a category at both conceptual and very often spatial levels. Some anthropologists, such as Lawrence Cohen (2000), go so far as to argue that "ageing" is hopelessly entangled in specific cultural assumptions and anxieties. He further suggests that a gerontology that pretends to universal applicability does so only at the peril of its conceptual impoverishment. We argue in this report that "becoming old" is only understandable in the interplay of personal experiences, specific local contexts, and broader social-cultural trends. For example, in the so-called developed economies of the last 100-odd years, "old" or "older person" has been firmly tied to productive labour in capitalist economies. For example in the 20th Century, both British and American English have

regularly used "retiree" or "pensioner" to refer to that stage of life, with similar terminology existing in other European languages. Of course, not all older people stop working and many did not have the sorts of careers that conclude with a work pension. We do not lack for newer, seemingly more "inclusive" terms for growing old. "Successful Ageing" was seen as a solution to some of these dilemmas in the 1990s until very recently, but, as Katz and Calasanti (2015) have argued, this may be due more to its vagueness in terms of the definition of "success", rather than its ability to illuminate a topic. Who judges such success, and against what measure(s), are much more difficult issues that are not resolvable by simple policy logics that seek self-evident categories to manipulate.

It is best, therefore, to imagine "old age" in terms of a modulation of the life course rather than a clearly defined state. It is possible, even likely, that one starts living with impairments, but the mere accumulation of such impairments does not necessarily move you into the category of "old". "Life course", thus, is a dynamic concept (an accident can indeed introduce a dependency step that "makes one old", but this is not simply a function of perceived severity). Ironically perhaps, many of our research participants comfortably label other people in their environments as "old people", based on their own perceptions of relative capacities to act and interact within their environments. Finally, a neglected part of that moment of the lifecycle we bracket as "ageing" is the importance of inter-generational communication, especially in terms of what is important in life and what people want to pass on to younger generations. Sometimes, these concerns are expressly religious, but they are always bound up with the unique human capacity to exist beyond physical death in the memory of intimates and in the warp and woof of stories that families and communities weave around themselves. We therefore also address these inter-generational practices and processes in this report.

Ageing in the European Space

SHAPES is funded by the EU to understand ageing in Europe, with the aim of developing a digital platform and ecosystem to support older adult's independent and healthy living in Europe. The space of "Europe" is, however, so diverse, in terms of culture and language, funding models, the balance of primary and higher levels of care, and the types of living arrangements of older people, that any claimed unity around "ageing" strikes one as forced. Notwithstanding this diversity, Europe has in fact one of the most rapidly ageing populations in the world, and, due to a combination of widespread access to at least some publicly funded health care and longer life expectancies, the so-called "Silver Tsunami" argument of the potential of an ageing population to "blow up" healthcare budgets, is seen as very pressing within this space. While our work was not focussed on the idea of Europe per se, "Europe" clearly motivates the specific shape of the SHAPES project, and Actions like this project, are part of making this space tangible to participants. Our own task, for example, has not just introduced many coal-face carers to ethnographic ways of working and thinking,

but has also put such professionals in different European settings in contact with one another, in a fashion that would have been unlikely otherwise.

1.2 Methodology

The research done for this report was led by the task 2.1 team of social anthropologists at Maynooth University. Methodologically it has investigated the lifeworlds of older adults through qualitative, ethnographic interviewing. The research team for this task consisted of the NUIM T2.1 team (three social and cultural anthropologists) doing research in Northern Ireland, Spain and two sites in Germany, and ten additional researchers embedded in SHAPES pilot and reference sites in Czechia, Finland, Greece, Italy, Northern Ireland, two sites in Portugal as well as a representative from the World Federation of the Deafblind. The core T2.1 team guided and trained the researchers and developed a toolkit used by all to ensure coherency in the data collection. It consists of an information sheet, a research handbook, a consent form, and an interview guide. These materials were all originally written in English and translated into seven spoken languages as well as Spanish and Italian sign language. Alongside formal interview sessions that were recorded, transcribed in the original language, and then translated into English, researchers also took fieldnotes on their observations and collected photographs from some of the participants.

Due to Covid-19 safety restrictions across Europe, all but a handful of the interviews were conducted remotely. As we alluded to above, the coronavirus pandemic, in forcing us to go online, also allowed us to expand our number of participants. This required an adaption of the Ethical approval protocol, which was subsequently gained for all of the fieldsites as well as for those interviews conducted with deaf and deafblind participants. The extended team of researchers were in regular contact with the core team, and with one another, so, we were able to maintain consistency in terms of how the interviews were conducted and in the supplemental material gathered.

Recruitment strategy

Recruitment of participants for the qualitative research in task 2.1 has relied on local pilot partners, SHAPES consortium members and, sometimes, snowballing (or chain referral) methods. Rather than following representative sampling techniques, we developed a list of social/cultural and demographic categories as recruitment guidance to our on-site partners. These parameters sought to achieve a wide spectrum of different life circumstances including gender balance, urban / rural environment, living situation (alone, with partner, with family members, or other living arrangements); diversity in ethnic backgrounds, class and religious belonging; diversity on digital skills, as well as a stratification in financial wellbeing. We also aimed to recruit participants with a range of health status and dependency levels, including both people with serious and chronic health conditions or mobility restrictions and fully healthy and independent older adults. It should be mentioned that for ethical reasons we did not

work with anyone suffering from dementia and all participants in this research had good cognitive skills and were able to reflect on their own condition. Where we do discuss dementia or cognitive decline in this report, the data is derived from the narratives of research participants about the experiences of spouses, relatives, or other acquaintances.

This report then is the result of the analysis of this qualitative interview data, fieldnotes and accompanying images from 94 older adults living in 90 households across Europe (Czechia, Finland, Germany, Greece, Italy, Northern Ireland, Portugal, Spain). 38 are Male and 56 are Female. The average overall age of our 94 participants is 75. 37 individuals live alone, 44 live with a partner, 13 with family members or in other arrangements. About half of our participants live in urban or semiurban areas and half in villages or more remote countryside areas. The majority of participants live in houses (53) compared to apartments (39). Two of our participants live in nursing homes / assisted living facilities.

The names of all research participants, their family members, and other individuals they talk about have been anonymised and they are presented in this report through pseudonyms chosen by the researchers or the participants themselves. A Participant Index (Annex 1) provides an overview of all interviewees, their gender, age, associated research site and where they appear in the report.

Interviewing and Analysis

The interview guide covered nine themes (1. Coronavirus Pandemic, 2. Life-history and Identity, 3. Family, Neighbourhood and Community, 4. Everyday Life, 5. Forms of Labour, 6. Home, Objects and Technology, 7. Transport and Mobility, 8. Health, Care and Wellbeing, 9. Imagining the Future). Research participants were encouraged to develop any connections that they wished, and, in practice, the order of the discussions and the balance between the themes varied. 378 hours of interview recordings were collected and fully transcribed, and all, but the Northern Ireland sample, had to also be translated into English, checked, and formatted for final use and analysis. The case studies then were developed into an NVivo database for indexing and preliminary analysis. Categories for initial analysis emerged from regular meetings of the core team, with the full research team coming together once a month to present specific cases from their work to elicit important meanings in their interactions and to gain an increasing feel for the individuals we represent in this report. The resulting findings, patterns, relevant topics and key themes that surfaced from the nine themes were clustered and cross analysed and are now presented in the seven chapters of this report that cover the experiences, philosophies, challenges, ideas and suggestions presented by older people themselves.

Some of these presentations went on to become #ShapesStories, an initiative spearheaded by Task 2.1 to develop a section on the SHAPES website dedicated to

the experiences and narratives of older people. Finally, all of the research team met for an extensive two-day workshop in June of 2021 to review case studies, identify cross-cutting themes, and contribute to the preparation of this deliverable.

1.2.1 Deliverable Objectives

WP2.1 was tasked to collect and disseminate ethnographic understandings of individuals, environments, and real contexts of ageing for each Lead Pilot Site on the SHAPES Project. This deliverable has fulfilled this contractual obligation and considerably exceeds these requirements, reporting on these sites, along with participants in three other countries (Czechia, Finland, and Italy).

We were also required to develop and support a central operating ethos of 'look-understand-act' for the development and implementation of the SHAPES Platform, providing insight into how older adults live across Europe and encouraging reflection where the Platform would attain low impact results. This report and analysis of the lifeworlds of older adults in and around the SHAPES pilot sites answers this commitment.

1.2.2 Key inputs and outputs

The inputs for this report have been listed above, 378 hours of interviews, supporting data gathered by the primary researchers, and 20 months of work of the Research Team.

In addition to this report and development of 94 case studies of the lives of older adults in Europe, key outputs include:

A section of the SHAPES website, titled #ShapesStories, where some of the narratives of older persons and subsequent insights included in this report appear. This part of the website was conceived as a way to make our emerging data more readily available to the rest of the SHAPES ecology and showing some SHAPES' research to a broader public audience.

Findings and case studies from T2.1 formed a significant part of the SHAPES Dialogue workshop on 26th October 2021. Within the consortium, the T2.1 team and data have provided systematic input into other SHAPES Work Package and Task meetings (especially Work Packages 2, 3, 6, and 8), the development of personas, and the continuously emerging SHAPES swim lanes for all use cases.

Finally, the T2.1 Team has carried out several academic presentations, including Annual Meetings of the Anthropological Association of Ireland, the Maynooth Ethnographic Winter School, a paper presentation at the International Society for Ethnology and Folklore (SIEF 2021), among others. The data has also been used in

teaching opportunities, and, over the course of the next two years, will be developed into a variety of academic publications.

1.3 Structure of the document

Each chapter of this work is self-contained to allow the reader to engage with any section relevant to their needs. A keyword page and Table of Contents at the beginning of each chapter indicate core themes and guide consortium partners to quickly identify information relevant to their interests. Each chapter then starts with a vignette, a short scenario-based story. This is to reveal this participant's values, social norms, and lived experiences in detail. The rest of the chapter focuses on topics that emerged from patterns and findings from our analysis and include detailed viewpoints and experiences of a variety of research participants to exemplify these points. The chapters conclude with some insights and reflections that should be useful for policymakers, solution developers and service providers.

Consider reading all the chapters in this report. Readers will find that selected participants are mentioned in multiple chapters. Recognising this should encourage readers to avoid reductively focussing on single aspects of an individual, to the detriment of fully understanding varying interdependent factors that impact their lifeworld. To facilitate such cross-reading and understanding of the interrelated topics in the life-worlds of older adults, please consider using the participant index at the end of the report (see Annex 1). Following individuals in the different chapters is a good way to understand interdependencies and multiple causalities and how the lifeworld appears as a unified field from the perspective of the person. Furthermore, while insights emerge mainly through close reading of the narratives and contextualised examples in all chapters, the insights and reflections section at the end of each chapter reiterates core themes of interest to our SHAPES partners (especially to pilot leads and use case developers) and offers questions for reflection for policymakers, solution developers, and service providers to whom they are addressed.

1.3.1 Chapters overview

Chapter 1 (Introduction) offers an overview of the report, the core aims and outputs, a methodology section, and a discussion of core concepts such as lifeworld, agency, and ageing.

Chapter 2 (Social Worlds – Living, Learning & Liaising) addresses how older adults' lives look like when seen through their relationships, daily activities and hobbies, and engages with learning, their use of technologies and the barriers and frictions they confront. The chapter highlights the importance of adaptation, motivation, participation, and choice in the later life course.

Chapter 3 (Moving through the World) explores the experiences of older adults with mobility, access, and the barriers encountered. It analyses physical and bodily challenges, the use of technologies, and creative strategies older adults develop to negotiate and maintain a life of independence and quality. It engages with the limits and constraints of moving around at home and in public environments and discusses how fear of falls, disabilities and other health issues affect their perceptions of ability, choice, and participation.

Chapter 4 (Working Worlds) discusses three domains of work and labour involved in the later life course (managing domestic life and family support, volunteering, and paid work). It highlights how people's daily tasks differ depending on their living circumstances and localities and how older adults participate in manifold and meaningful ways to societal processes, giving them in turn financial compensation, appreciation, and recognition as well as purpose and meaning.

Chapter 5 (Financial Worlds – Spending & Affording) addresses challenges with income and material (in)securities, management of finances in the later life course. It demonstrates how older adults support their offspring and emphasises the importance of engaging with gendered dimensions of poverty due to unequal opportunities and pension schemes as well as the difficult choices some older adults have to make to cover daily expenses in old age.

Chapter 6 (Informal Care – Providing Care) explores caregiving practices of older adults. It demonstrates how senior citizens participate in and facilitate care practices in the family and society and how their contributions are key to maintaining care structures in Europe. It also demonstrates older adults' recommendations for useful technological support and how certain improvements in support systems would ease these practices in home settings and enable self-care and social integration.

Chapter 7 (Formal Care – Receiving Care) explores the experiences of older adults accessing and navigating 'formal care' through hospitals, GP practices, and nursing homes. It discusses the value of peer support, gaps in services and issues of communication, trust, and empowerment. As such, the chapter highlights the need to engage with rather than to manage older adults in the context of health care.

Chapter 8 (Legacies and the Future) focuses on the entire lifecycle of older adults and engages with both memories and thoughts about the future. It explores the meaning of leaving a legacy, older adult's advice for the next generations, and the importance of building the future on lessons from the past. The chapter then explores the end of life, inheritance, loss, and bereavement and discusses how older adults think about transformations, crisis, and change.

Chapter 9 (Conclusions) provides a window into how older adults think about age and ageism and offers and a summary of the core findings and themes of this report.

SOCIAL WORLDS – LIVING, LEARNING & LIAISING
Chapter 2

Chapter keywords: Daily Life, Adult Education, Digital Upskilling, Family, Friends, Routines, Hobbies, Learning, Exercising, Purpose

2 SOCIAL WORLDS – LIVING, LEARNING & LIAISING

LUDWIG

Ludwig (69) is a chatty and highly educated former manager of a food company who lives in a beautiful house with a large garden 30 km outside of Dresden. He and his second wife met online and created a patchwork family with four children and nine grandchildren. The couple enjoys spending time with their large family and Ludwig – a picture-perfect 'active older adult', follows his many hobbies regularly. With curiosity he explores new digital programmes, invests time in volunteer work and teaching activities, and above all, in minding his garden and bonsai collection. A critical but positive thinker by nature, Ludwig made it his goal to be content and even on uneventful days, follows his motto "You need something to look forward to every day."

Born in 1951, Ludwig was raised in Saxony, where he lived his whole life, before, during and after the German Democratic Republic (GDR) regime. The passionate microbiologist became the director of a flourishing food company. With his sense for innovation, he managed to get the company through the economic changes of the breakdown of the socialist regime in 1990, in which all too many factories crumbled. To this day, Ludwig is politically engaged and talks at length about the mistakes and lost opportunities during the reunification of Germany, including gender equality, workers' rights, the educational system, and integration. And he worries about the rise of right-wing populism and extremist ideas he encounters even in his own extended family.

The hobby botanist has a large bonsai collection and is an admirer of Japanese gardens. He spends days and weeks trimming his bonsai, caring for his koi in the pond and the other plants in his 1300 m^2 plot of land. Given the responsibilities, during the summer months the couple does not go on holidays as they prefer to look after the garden and mind the grandchildren. With nine in total, they help their children by minding two at a time per week throughout the summer. "That way, our summer is practically full anyhow". Additionally, Ludwig loves to guide visitors and an interested public through his own little nature paradise. The amateur photographer put together a folder as well as a power point presentation with pictures he took of his garden, various plants and the layout photographed from above with his drone. For his own entertainment as well as for security reasons, he recently built a weather station in his garden and installed surveillance cameras to guard and observe his treasure.

Retired in 2015, Ludwig hasn't stopped working. Today he contributes to various advisory boards, is the head of committees and volunteers as a teacher at the Seniors' Academy in Dresden. He feels comfortable in the digital world and emphasises the importance to educate older adults in the use of digital applications and online

communication platforms such as Skype and Zoom. Among other things, in his free time he gives training courses for older adults on how to use digital means of communication. During the coronavirus pandemic, he says, many senior citizens discovered the joys of videoconferences. At a time, in which personal contacts were limited or even prohibited, applications such as WhatsApp or Skype allow for families to meet, to see each other and to share images as well as videos. Ludwig is convinced that the pandemic provided an opportunity to interest and engage more older adults in using digital technologies.

> "Yes, definitely. As I said, I have a colleague who is 86 years old. She used Skype for the first time. And she was really excited when we had the first project meeting online. (…) I hope this trend – from digital telecommunications to e-health – will keep up beyond this Corona wave."

As can be seen, playing with apps, digital tools, and associated technologies is one of his passions. As a profound believer in progress, Ludwig participates in a working group to support the implementation of telehealth and, during the coronavirus pandemic, seized the opportunity to test some innovations in e-health with his doctors. Ludwig counts himself in the risk group, and he has a healthy respect for the virus, but when the pandemic broke out, he did not accept paralysis but embraced the chance to test online consultations.

> "You can do a lot, for example at the dermatologist, I tried out how it works. Okay, the dermatologists themselves are still a bit hesitant because this is also new territory for them. So, when I spoke to him, he said to me straight away, 'Well, yes, we don't know, come here'. but I said, 'I would like to show you a picture with my smartphone and just have a look'. Then I showed him, and he said, that's no problem at all. Well, you see, I do not have to come to you, you now have resolved it within two minutes, and my question was satisfactorily answered."

Ludwig admits that in the majority of cases people will still have to go see a clinician in person, but he also believes that many 'trivialities' can be answered satisfactory online:

> "I'll say, smartphone cameras are actually great these days, so that you can certainly see a lot through such an image. And if not, ok, then you just have to visit the doctor. Then it makes sense to go there."

With all the good and bad that technologies bring, Ludwig believes that a profound cultural break has happened between his and the next generation. However, even though he sometimes feels disappointed by the loss in his childhood values, Ludwig is also full of hopes for the future and always keen to follow the latest innovations. In his view, robots and computers might profoundly shape the care sector and self-driving

cars could become a solution to the problem of mobility for those who do not have a license.

2.1 Introduction

In design terms, Ludwig could be considered a prototype for an active and healthy older adult. Like him, many older adults involve in clubs, societies, church activities, volunteer work, grandparenting, gardening, sports, travelling and many other leisure activities. However, not everyone wishes to engage in so many social events. Many senior citizens in our research appreciate a quieter life with routines and siestas, a good tea in the afternoon, a walk, the habit of reading a good book, or an interesting documentary on TV in the evening. Our data thus confirms that aging is not a uniform process, but rather, as Buch put it, one "profoundly shaped by local environments, access to resources, and social relations" (Buch 2015:278). Depending on their health, interests and network of friends and family, their experiences are shaped by the "depth and breadth of social support available to them, and their access to economic resources" (ibid). Hence, understanding older adults' lifeworlds holistically and considering people's individual choices to lead a life they value is essential when thinking of technologies, social interventions, or health services that aim to improve their wellbeing.

This chapter sets out to portray people's diverse lifeworlds in social and cultural context. The first part explores the meaning of family constellations, friendships and support networks and asks how technologies can help against loneliness. The second part discusses hobbies, sporting and leisure activities in private and public settings and explores the key topic of learning in later life. We analyse how and for what reasons people engage with digital technologies and the barriers and challenges they encounter.

2.2 Family, Friends, and other Relationships

Social relations, family connections, and love are key to a fulfilled social life. As the introductory story shows, Ludwig lives in a loving relationship with his second wife. Aged 54 at the time of the divorce from his first wife, he first had to be convinced by his children to engage with online dating. However, given that, as he says, "personally, I could never imagine living alone permanently. I need someone, I need to share all kinds of things with someone" he gave it a go and without much hope, created a profile. Ludwig didn't have to wait long as amor soon brought him to meet his current wife, who lived just ten kilometres away. The couple got along immediately and to this day, still celebrate their anniversary in the Castle where they had their first face to face rendezvous.

Love, dating, and sexuality are topics often underrepresented in studies of ageing and the later part of the life course. The desire for loving companionship, however, has

come up many times in our research. Leonor (66) from Portugal is living through a difficult and emotional time of coping as her husband suffers from an advanced form of Alzheimer's and has moved to a full-time care facility. And so, even though she is still married to him and visits him regularly, in a way she already lost her partner and is now trying to balance her loss and memories with her desires and yearning. Telling us about her situation, she recounts a friend's advice: "you are alive and you are an attractive woman; for sure, your husband would like you to find a new lover." Aware of the restricted opportunities for new encounters at older age, Leonor's friend pointed her to online dating: "She convinced me to use a new smartphone App., called Happn, which could help me to meet with someone. 'It's funny' she told me, and I confess to you, I used it once." So far, Leonor has not found a new partner, but her attempt to balance her diverging needs demonstrates how different meaningful relationships can co-exist together and can be supported by platforms for older adults.

Thinking about supporting loving relationships, most interview participants mentioned their children as their most trusted companions. Such relationships are all the more valued when guided by mutual reciprocity. Jana, a 73-year-old woman who lives in a small village in the Czech Republic, highlights this point when speaking about her experience with the pandemic. Embedded in family life, Jana and her husband care for the young generation and in turn, receive support and love from their children. However, as she says,

> "I didn't expect that our daughters and their husbands would take care of us like that. In fact, I still take care for them. I do them good things, I bake them (…), I cook for them and then I deliver the pots. Then I ask my grandson, '[Grandson], what do you like? I'll bake it for you', then I bring it. But [during the pandemic] they took good care of us, so we didn't have to go out, and because it was spring, the garden helped us too."

Contrary to Jana's experience, for some older adults, family duties weighed heavily, such as in the case of Rosa (75) from Portugal. Rosa grew up in extreme poverty, with little schooling and the experience of child labour, both in the domestic and the agricultural sector. She later migrated to the city in search for better living conditions where she was a public employee her whole life. Rosa is very religious, married early in life and had two daughters, one of whom suffered from drug addiction and became a prostitute. Now retired and a widow, Rosa recently experienced personal loss as her daughter died from cancer during the Covid-19 pandemic, "my daughter died in February, but what really cost me the most was to close the discos for older people, because I no longer have anything to distract myself". Left with no distractions, the mourning process adds to the problems she has with one of her grandsons, who is diagnosed with schizophrenia, and, living in the same household, regularly stole her belongings. As a solution, she officially offered her house to her second daughter and moved into the small annex, saying "You go to the house, pretend it's yours, and help me control my grandson, because I can't." Now alone in the annex she frequently feels

despised by her family who all too often exclude her from gatherings and seldom invite her for dinner. And so, even though Rosa continues to support her grandchildren, great-grandchildren and daughter financially, these moments of contempt are to her the embodiment of loneliness.

Some of our participants are most content on their own and opt to live alone rather than seeking a new relationship, such as Charlotte (67) who loves to live alone in her big and in her words "luxuriously oversized" 150 square meters countryside mansion. For the independent and strong mother and health specialist a new living arrangement is not an option for.

> "Living here with a partner? No, I don't want that anymore. I don´t want it. Well, I lived here with two men. I think that's enough. [laughs] No no, I definitely don't want that. I feel good here on my own."

For some, single person living after a difficult relationship was a relief. Polly (83) and Monica (78) in Northern Ireland, both divorced after challenging marriages, separately enthused about the pleasure and freedom of living alone in their own homes in later life. For Monica, her day is punctuated by visits from her paid caregivers, friends, and gardener. Until recently her ancient cat 'Mops' has also provided 'round the clock' steadfast company. Unfortunately, her long-time pet and social companion died from natural causes during 2020 leaving Monica distraught. Determined to get another cat, she has decided to provide a home to an older feline from a Cat Rescue Centre because she feels that a young cat would outlast her. Polly on the other hand prefers to avoid pets because of the responsibilities they create.

In Greece, 73-year-old Kalliope a keen gardener and cook with a passion for music lives with her middle-aged son Gas in a small apartment in the centre of Larissa. Kalliope's family comes with a troubled history. Her late husband has served 12 years in jail on drug related matters and her son has been addicted to drugs for nearly 20 years. He tried many times to go into rehabilitation programmes, so far without success. Her son's addiction has already gotten him into robberies and even stealing from friends and family, including Kalliope's jewellery and electronic equipment in order to secure his dose. This is the reason why even today Kalliope cannot bring herself to buy a computer or a smartphone:

> "We don't have a computer. We used to have one, but Gas sold it like he did with everything else (…) in order to be able to buy drugs. Therefore, I never bought anything else. I now own a mobile phone, which only costs 19 euros. He can sell it if he wants, but who is going to buy it?"

Despite such difficult situations Kalliope does not give up. In the past 12 months, the situation is improving as he has 'been clean' and able to start working again to which Kalliope adds: "if he is fine, I am fine too". And when she needs a break, she simply

gets into her car and drives "until I get to my favourite bar to listen to good rock music and drink a glass of wine".

In Dresden, Hannelore (76) and Frau Blume (80), who chose her own pseudonym, enjoy living alone but in each other's company. As best friends, they have known each other for more than 50 years, had their children at the same time and now even moved into the same suburb in order to live in close proximity with each other. One divorced and the other a widow, they spend most of their time together, call each other daily and go on many trips and excursions. "We know each other better than an old married couple," Frau Blume explains with a laugh. Sharing her daily life with her best friend and having a regular companion with whom she can go to concerts, daytrips, or call when she feels unwell, is her biggest joy. However, Frau Blume is fully aware that the day might come when she would no longer be able to stay in her flat on her own. "I have this agreement with my daughter that when I can no longer live here alone, I'll move up to Bremen to live with her." When we asked her why she would prefer this option as it would take her out of her social environment and away from her dearest companion, she explains her choice:

> "Well, my friends are all old. We are all in this age group, and many have their children here too, well, they are looked after as well. That's okay. But I don't have anyone from the family. And in the end, the children have the responsibility for the elderly, I had it for my parents too. I know how difficult it is when you are so far away. You always have a guilty conscience. So, I said [to my daughter] 'I don't want to put you through that. I'll come to you, so you can come see me, even if you're just passing by on your bike for ten minutes'."

2.2.1 Loneliness, Communication and Technologies

Loneliness is one of the biggest challenges in the later life course. "And now you also notice that I am speaking for the first time today and my voice falls, it becomes more brittle," 85-year-old Susanne told us laughing one day when we did our interview phone call. For her, often days go by without any conversation or social interaction. Susanne lives alone in a small town in West Germany and while at times she enjoys her independence, she often feels lonely since her husband died three years ago. Only recently has she started to build a peer group where she can chat and play cards together once a week.

> "I was quite alone before that, but I got to know a lady who said, 'You are so alone. We want to take you into our group to play' and the other women agreed."

Danae in Greece found a similar strategy against isolation. The 69-year-old lives alone on the top floor of her two-storey terraced house. After her husband's death Danae stopped working and experienced episodes of severe depression and loneliness. As

a solution she decided to convert her space into a place to meet her friends, have coffee and eat sweets and pies with the ladies. "I love cooking for family and friends." Despite suffering from diabetes (see also Chapter 7, Formal Care Worlds), food to her signifies sociality and provides a way for her to connect with neighbours. Unfortunately, since the onset of COVID-19 she is no longer able to host these meetings with her friends.

According to De Jong Gierveld and Van Tilburg (2006) health practitioners should be aware of the differences between 'social loneliness' which can be caused by the lack of a social network and 'emotional loneliness' which can occur even amongst those with large social networks and is often associated with anxiety, depression, and bereavement. The two types of loneliness require very different approaches to intervention. The latter is seldom easily helped by technological solutions, whereas social technologies can make a real difference in situations of social loneliness and isolation, which not only lead to solitude and seclusion, but also put people at risk in case of unexpected health issues (Garattini, Wherton & Prendergast, 2012). 70-year-old Bert from Northern Ireland has experienced such an incident when he had a fall in his home. Living alone and with his phone out of reach and no one coming by to check on him, he was forced to lie on the floor for three days without help. Near dying, he finally managed to pull together his last strength and call an emergency ambulance. Paul (80) also knows that living alone in a house or flat is a health concern. The former radio engineer has travelled the world, and, after getting to know his wife in Brazil, married late. Together they had a happy life full of variety, but the couple had no children, and most friends live far from their home in the Oberbergische Kreis region (ObK) in West Germany. Paul however is lucky. Now a widower and with his house situated on a rather remote hill outside a small town, his only direct neighbours have "adopted" him to the family. Having become an honorary grandfather of ten children, he enjoys regular visits, eating and cooking with the "lady of the house", and the monthly whisky tasting that he and the older boys established. Furthermore, Paul tells us,

> "The most important thing is that they keep an eye on me. If the shutters don't go up in the morning, their alarm bells go off. That's important, right? because otherwise you could lie here for days."

Like Paul many older adults have created some kind of safety net. In Northern Ireland, 71-year-old Ted lives within a neighbourly sociality.

> "The guy across the street has Alzheimer's, he's 91. I would join him occasionally and just have a chat and I am in touch with his family because I keep an eye over him. If the blinds are down for any length during the day, I would ring one of the daughters and ask her to make sure he is okay. (…) The neighbours around here, we all have each other's telephone numbers so if

anyone needs help, they can ring one of the other neighbours. So, the street keeps in contact."

Not everyone has the luxury of direct physical proximity with their neighbours and loved ones. However, using digital tools to keep updated on each other is common practice among many older adult families, friends, and acquaintances. Hanna (81), lives in a small town in Finland with her two dogs. Separated from her husband for many years, Hanna she now follows her hobbies, participates in a literature group, and enjoys reading her books. One day, her grandchildren invited her to a family group that acts as a digital "safety net" to keep in touch and to watch out for her wellbeing. "So that's been going on for almost two years, this group called the Heart Group." Since she is in good health, at first, she was hesitant when the grandchildren asked her to install WhatsApp on her phone to enable the group chat. However, no matter her initial refusal to the utilitarian purpose, she now values the companionship that comes with her Heart Group.

> "It's very precious, I think. We'll send a selfie, fresh out of bed, or like a coffee cup, or, um, whatever, just anything really. Like, here I am!"

Neighbourhood initiatives, community gatherings and family support groups, often facilitated by digital technologies, are all strategies against loneliness and improve the wellbeing of older adults. Social platforms friends, family or the neighbourhood additionally provide a feeling of safety and independence and at the same time ensure social contacts and meaningful encounters on a regular basis.

2.3 Society, Hobbies, and the Importance of Choice

Retirement is a moment of great change. As a *rite de passage* (van Gennep 2019) or moment of transition that marks a milestone or change in a person's life, older adults' employment status changes and so does their income and social standing. Our data showed that many older adults have enjoyed this moment greatly as it opened time to explore new interests, hobbies, and tasks. Mike, a 77-year-old husband and father of two from Dresden is a trained nuclear medical engineer. All his life he worked hard and enjoyed his profession, which also earned him a high position and a good salary. As his work was in Berlin, Mike however became tired of commuting and spending his week away from the family. When at the age of 63 the option for early retirement opened, he accepted with excitement. As he moved back to Dresden, he remembers how he put all his time and energy into the many hobbies he finally had the time to accomplish. However, laughingly he recounts how, after half a year these things were completed and then the "great boredom began". With his wife still working, Mike felt that he had to set new goals in his life, recreating a sense of purpose.

> "That's when I came across the Seniors' Academy. At the beginning it was very exciting and interesting and I listened to a lot of lectures there, real lectures with

young students, and at some point, I said to myself, 'Well, just taking part is boring too'. And then I became active there in the association, and that ended with me joining the board and becoming a European Network for Older Students representative."

Many research participants mentioned similar experiences and the importance to remain useful and to actively contribute and work (for more details see Chapter 4, Working Worlds). However, others like Hannelore highlight the value of choice and freedom she now experiences. During the summer months, the 76-year-old woman volunteers in the Schiller house and comments upon the difference between work and work after retirement this way:

"Back then, as I said, life was like a hamster wheel. And now I can enjoy with joy that I have the time, in everything I set my mind to. But I have the joy of having time. I have a HUGE joy in being independent. I don't mean from people, but that no one can order me around anymore. … That kind of doing everything voluntarily and also saying, 'no, I don't want to do it, I won't do it.' So, it can be nice to refuse to do things and on the other hand to give yourself over to things that give you pleasure. That's something I didn't think about in the past, of course. Simply because it wasn't possible or because I didn't have the time."

The quote exemplifies that, no matter how people organise their daily lives, many regularly emphasise their gratitude for the liberty and ability to say no and on the other hand the pleasure of being able to follow their desires. Social apps designed to offer entertainment and communication in the local region, can widen or provide these choices and can drastically improve older adult's life quality.

The coronavirus pandemic with its lockdowns, government-imposed isolation policies, and travel restrictions significantly diminished this freedom of choice. Travelling as a key element of entertainment at the later stages of life disappeared nearly completely, as did most other social and cultural activities. Clubs and societies closed, volunteer work was stopped, and even church activities and mass no longer took place. For Xenia (66), a recently retired restaurant owner in Germany, work is important and despite official retirement, she realised the desire to contribute actively to society. Now an Ambassador for Women's Entrepreneurship, for the past two years, she has been involved in voluntary work for women and older people, giving courses on digitalisation and organising events, but after a year of pandemic Xenia sums up how it:

"All came to a standstill because of Corona! And that means I'm not working. That's a very strange state for me, I don't know it at all!"

Due to Covid-19 measures, not only workplaces but also churches closed. This was a devastating experience for some older adults to whom these places of worship are a central part of their everyday life where they engage in community work and charity activities or simply attend the Sunday mass. This was the case for Nigel (83) from

Northern Ireland, a devoted believer, for whom the Bible is his source of strength. Nigel is currently fighting cancer and being cut off from the religious ceremonies he attends several times a week in normal times was shocking and demoralising. However, online services have brought some relief in this difficult situation:

> "I can watch so many different ceremonies, you see, different programmes that goes out from America and Australia and Canada. I get them online on my computer, I can have 10 different stations I can go to. Yes, and from London, and our church has a broadcast every week as well."

Momi, a 75-year-old married Italian man with deafblindness, knows the feeling of isolation intimately. Momi was born deaf and learnt sign language only at the age of 8. He worked for the Italian administration for many years but at the age of 30, his vision was severely reduced, and today, he has become completely blind leaving him with Italian tactile sign language as his only means of communication. Momi married recently and his wife acts as his guide interpreter in social events. However, as cultural entertainment is often inaccessible to Momi, he developed a strong passion for handicrafts and creates sculptures using wicker and clothes pegs. Enthusiastic and positive in nature, Momi is content. Today he is a sign language and handicraft teacher for younger persons with disabilities where he passes on his knowledge and experience to encourage younger generations to take control of their lives. With the coronavirus pandemic, however, all courses have been stopped and Momi's communication is further restricted. He hopes for it to pass soon, so that he can again communicate by touch with more people.

2.3.1 Dancing, Sports and Exercising

Considering choice, our research participants allude to frictions they experience between "doing the right thing" – such as taking care of family members or supporting the children financially and with their time – and the idea of "having fun while I'm still around". The latter includes things like dating, dancing, and refusing to "act" one's "age". Rosa from Portugal, who as detailed above, struggles with a difficult family situation and due to the coronavirus pandemic has been cut off from her favourite pastime, dancing, describes this calamity vividly:

> "I really like having fun, I really like going to a disco, dancing with this one and that one … but it's just dancing, that's all, it's over. As soon as I finish dancing, I go home … and this man … 'Are you going to eat? Shall we have dinner?', and I told him: 'You go to your house and I stay at mine'. I'm not interested in anything else."

Dancing is an activity many older adults enjoy. The widower Sandro (87) who lives in a flat in Bologna with two of his children, volunteers at a senior centre where there are

many activities, including memory training, gymnastics for seniors, a 'University' for older people, and dancing. Sandro used to go to ballrooms all his life,

> "I've learnt to dance Boogie-woogie. Some girls from Bologna used to come dance, but in the countryside [where I lived back then] no one used to dance Boogie-woogie: I learned to dance it … so I could pick up girls!"

Like Sandro, many older adults mentioned dancing as an activity that brings pleasure and evokes memories of former times. Margaret from Northern Ireland also remembers the lively environment such occasions provided in her youth, where she went to dances and hops. She now regrets the lack of facilities to follow her hobby. "There is nowhere to go for older people," Margaret tells us, pointing out thereby the lack of fun things to do for older adults in her area.

Playful exercising and a healthy diet are important to many older adults as they increase their interest in bodily wellbeing. 79-year-old Robert and his wife assiduously support their health. The successful author, translator, and comedian exercises for at least two hours a day and takes around 18 food supplements, vitamins, and minerals. Robert grew up with a single mother in the post-war years. He suffered from rachitis, a disease of the bone structure caused by vitamin D deficiency. This is also why he claims to be unathletic, even though he opens our conversation with an account of his two-hour morning swim, one of his regular activities along with KISA training, jogging and long walks. "My wife is even worse. Now, for example, she just went for another walk to get to her 10,000 steps today." Always challenging himself, physically and mentally, Robert also uses digital tools to pursue his sporting activities with childlike glee. "Have I told you how I make money running?" Having bought a FitBit watch recently, he can now measure his steps, his pulse, kilometres run, calories burned and the number of floors he climbed. "And here's the thing," he adds with a smile,

> "Our leading health insurance company here in Saxony, the cheapest one, so to speak, which used to be the local health insurance company in the GDR, pays me 1 euro fifteen times a month, every second day of the year, so to speak, if I fulfil certain conditions. Either I must walk 10,000 steps that day, or I have to run fast enough in a quarter of an hour to burn a certain number of calories. And then I enter that, and I get about 180 euros a year. And for that I can go swimming again for free. It's a piffling programme, they reward you and it's a lot of fun. My wife gets up and says, 'I've already earned another euro'."

To emphasise the importance of reward, Robert continues, "It's not about the euro at all. It's about the confirmation. Yes, I have 1700 points. The fact that it will be 170 euros is nice, but yes, they confirmed it and that's a wonderful feeling. Clever." While the social security company does not financially reward "real" sports like KISA training or swimming, these small-scale challenges are a great motivation to dedicate oneself to a healthy lifestyle on a daily basis, "even on the days when they don't pay, I tell

myself I'll stay in rhythm." And so, Robert has found a playful and profitable way to overcome his inner 'couch potato', which is not unknown to him either and, competing with his wife, he smilingly congratulates himself on every ten thousandth step.

2.4 Learning and Digital Worlds

Responding to imposed transformations in life and daily routines is an important part of learning. After the death of his wife a few weeks prior to our interviews, Franz (78), who lives in a small town in West Germany, had to adapt to a new daily routine. As for many older adults, such changes in the immediate lifeworld forced him to engage with activities formerly handled by his partner. In Franz' case, cooking was one of them. "I alternate between making something myself, although I haven't really got the hang of it yet, (and) getting something somewhere. There are restaurants here that deliver outside the house, where you can pick it up. It's also very popular here because of Corona. And then I sometimes go to an inn in town to eat something." Aware of the need and feeling capable of learning new skills, Franz, who never cooked in his life, started under his wife's instructions during the year in which he cared for her before her death. Today, preparing a meal and feeding himself, the 78-year-old man watches YouTube videos that guide him through the process step by step. With retirement, Xenia also discovered YouTube videos to revive one of her childhood hobbies. "Since I stopped working, I knit. My husband never believed I was doing it because I'm always so impatient. But I taught myself to knit again through YouTube. I could basically knit, I still learned it at school, but I never knitted socks and now I knit socks." And, laughingly, she adds: "Well, they are still all one-of-a-kind."

Learning and exploring new things can be supported by online tutorials and video instructions. Just like Franz and Xenia, many of our research participants have mentioned the joy of upskilling with the help of these new technologies. Such is the case for Monica from Northern Ireland, who loves to learn and frequently uses the internet and Google to explore the world beyond her doors. She also thinks Open University TV programmes have improved dramatically. Her tablet is constantly by her side and Facebook keeps her connected to her children and friends overseas. Seeing the internet as the primary source of information and knowledge, she bemoans however that companies have largely stopped producing instruction manuals.

> "I remember when I got my first iPhone, I went to the shop to get it. I remember asking the girl 'is there not a better instruction book with it?'. 'Oh No', she said - just what the young say as they are not bothered by that. And the shop girl said, 'I know it's difficult, more difficult for you, but I just play around it. And that's all you do. You just play around with it and you'll find out everything' and I thought, 'Grmpf!' You know. I'm not used to just playing around with stuff. I love to have instructions. You know, like a recipe. I want instructions to everything."

Accessible instructions to digital hardware, the functions of apps and new programmes are rarely available for many older adults. Furthermore, 80-year-old Walter who lives half an hour from Cologne and is a keen user of digital tools, is annoyed about the Anglo-centrism of the digital worlds.

> "When they have explanations, they make a little pre-text in German and then all the shit comes in English. And my English is not so good. I can understand some of it and things like that. But I think it's a disgrace that they have programmes for Germany or for the German-speaking countries. But then, when it comes to explanations or the like, everything is only in English."

As the examples show, accessibility is a cornerstone for the successful implementation of digital innovations. Especially technologies for older adults need to reflect on the lack instruction, language barriers and barriers created by visual and hearing impairments. 74-year-old Felipe from Cordoba in Spain, a deafblind widower and father of two, developed a depression as he felt isolated after the death of his hearing wife, a feeling that reminded him of his childhood, when communication with people outside the family was very limited. To improve his situation, he decided to move into another apartment and start over. With time, he also learnt to cook and do the house chores, and now enjoys doing it for his daughter and granddaughter who live close by. As Felipe lives alone in a flat, COVID has had a big impact on his mental health, as his possibilities of communicating were very limited. Face masks and social distancing have worsened the communication and he often struggles to communicate smoothly even with sign language users. To him, digital means of communication are key and certain hardware helps facilitate his needs.

2.4.1 Digital technologies, Challenges, and some Solutions

Older adults need a good reason and motivation to engage with and learn to use new digital technologies. Hence, technology adoption does not happen in an abstract sense but because certain devices are perceived to be useful. To that end, Giuliana in Italy explains why she does not use a computer: "I have Skype, but I've never used it because I don't use the computer. I have it, I also did a course to learn how to use it, but it's something that I don't need. I mean, I can use my smartphone to send e-mails, messages, everything I need. I have all these things in my smartphone. So, my computer is in mothballs now." In a similar way, Susanne from Germany explains her take on computers, tablets, and smartphones:

> "I have no computer. Oh, the purchase was too much for me alone. My husband had one and when something had to be done, he did it. I took care of other things and when he passed away, we gave the computer to our grandson. At the time, I didn't feel like bothering about it. It was enough for me that I have a smartphone and whatever else I have. And I wasn't interested in that. Now

sometimes I think it would be nice to have a computer. But you can also get a lot with the smartphone. You can take part in a lot of things."

As our data shows, many older adults do not reject technologies per se, but only adopt it as a proportionate response to existing or predicted needs. Reasons not to engage with digital worlds often go beyond the immediate usefulness of a technology or function of an app. In some cases, installing a stable internet connection is a challenge and the lack of economic means to afford the costs are part of the reasons to refuse digitalisation. Furthermore, in some cases high quality connections are simply not available in the region they live in, creating thereby unexpected obstacles. While in some countries broadband internet connections are standard, other regions and specifically people living in more remote areas are often cut off from the full use of online services due to the lack of solid internet connections or an income that doesn't permit buying proper tablets and smartphones. And so, even the best tools and apps fail their purpose if people's hardware and a lack of high-quality internet make it impossible for them to enjoy them.

For the first steps into digital worlds, older adults are often helped by daughters, sons, and grandchildren. Kalliope in Greece exemplifies the issues speaking about her smartphone:

> "My son showed me fifty times how to view messages on a simple phone that I own but I can't remember anything. I only know how to turn on the TV, change the channels and the volume. If you tell me to do anything else, I don't know it and I won't do it."

Frustrated with trial and error, and for reasons of her personal situation described in the previous section, Kalliope does not engage with digital tools. However, if "learning" was offered in an organised way, she confirms, "I would go and try. Because now it's not helpful."

In Aveiro, Artur (73) explained how family members helped him learn how to do video calls and the joy he feels now that he knows the ins and outs of it. "It's easier when you are able to see one another. So, through telephone, you hear the voice, but through WhatsApp, at least there is an image." At the same time, Artur is cautious about the level of intimacy that comes with video component of a call which allows the participants to not only talk but also enter each other's homes or locations visually. "You see, WhatsApp is usually with my children, with other friends I don't use video call, for reasons that, at least in my perspective, I don't want to go into areas that I don't know [show] where I am, where they are. Therefore, only audio call, the call that is other than video call." Natalia (78) from Czechia does not enjoy computers and due to her lack of interest she is reliant on her son to use digital tools when wanting to get things done online "The young generations have an entirely different relationship with these things, I just can't get myself to learning it". While she is well cared for with her

son handling her online banking or doing some shopping for her on the internet, Natalia is unhappy knowing about her dependency on family for digital support.

> "It's a tough cookie, I forget it, because already learning it on that computer when I don't know…So I'm already calling my son. He swears or yells, so he gets angry, but he tells me what to do, I push a button and that is it." With her son's help, Natalia also manages to start video calls to her friends, but: "again the other party must be able to do such things as well".

Access, lack of interest or motivation, missing a communication partner and dependencies to set up digital channels all create obstacles that can hinder people in engaging with digital communications. Furthermore, some older adults have reservations against unfamiliar telecommunications, apps, sensors, and online tools, with opinions ranging from worries about privacy settings to strong scepticism and outright vilifying technologies. Isabel (70) lives alone in a house near Aveiro and follows a simple life philosophy: "Time is given to us for free!" Isabel spends her time taking care of her kitchen garden and animals, cleaning her house and spending it with her boyfriend, daughters, and grandchildren. To her, the simple truths of nature are what count most in her life, and Isabel does not trust technology. She recognises that technology is important and that it helps many people but would feel trapped using a cell phone and claims to be happier with only a landline phone.

> "I feel good, why would I walk with a cell phone? For me, cell phones are liars, because I can say that I'm at home and I'm not, the landline is, the landline, we're at home, otherwise, I would not answer."

Equally sceptical, Ligia (75) from Porto uses digital technologies but is worried that they will reduce our ability to think. In her opinion, new technologies must be for the new generations and for the old generations. Ligia finds new technologies very pleasant and is convinced that they make certain things easier. However, she also has reservations, and laughed while stating,

> "We lose that experience of having to think, of having to think how I will get there, how I will do that. That pleasure of the person thinking 'Well, well, but how am I going to do this? How am I going to get there?' (…) because if I get to a keyboard and type something and say 'There, that's it, that's it …' – I didn't think, I just wiggled my fingers on a keyboard. I mean, these new technologies are beautiful on the one hand, they are practical, but they are … almost like creating a bunch of illiterates, let's say, unable to think."

71-year-old Ted from Northern Ireland also believes in technologies and their usefulness to connect generations but also expresses his worries that technologies would make people useless and the difficulties of learning to use them efficiently.

"Technology is in danger of becoming so helpful that it can make some people feel useless, unwanted and isolated. I think those working in the technological arena need to be brought to think about those things. My son in Manila is a web developer, even when he has tried to show me something on the computer before he left, he went on the computer and went 'zjoom' --- he can do it all but he's not a teacher, if you know what I mean. I think that should be a concern for the people who operate the technology."

However, as Ted points out, to remain independent, older adults wish to be taught in using digital technologies in a way that works for them. Aware that, as he puts it, "older people already feel incompetent to a great extent because of the world moving so dramatically around them", he emphasises the importance of upskilling so to engage seniors with technologies to a degree that they can participate in the modern world. As an adult educator, Ludwig emphasises the importance of peer-to-peer and professional education and made it his goal to hold talks on technologies and means of digital communication for older adults and recently presented Skype at the Seniors' Academy. With two laptops and two projectors to demonstrate the transmitter's and receiver's point of view to convey the usefulness of the available functions. Framed in a wider talk on the social aspects of social media, his audience learned not only about functionalities but also about the joy of applying these means of communication to their personal lives. From experience, Ludwig has some advice on teaching strategies: "Showing older adults the functions one time is not enough for senior citizens to go home and use them themselves cause even a small problem can bring their efforts to an end. And feeling that you don't get anywhere is actually very frustrating." This however does not mean that they are less willing or eager to engage with these new tools and means of communication "They just need more regular hands-on support".

Digital upskilling is a key to integrating older adults in the developments of a digital age, with all its possibilities of e-Health applications, online banking and digitally supported video conversations that will enrich their social lives, especially when living independently and often alone. Hands-on workshops, courses and lectures are important means to improve their quality of life. The coronavirus pandemic has created an additional motivation and pathway for older adults to play with digital communications.

2.5 Conclusions

The aim of this chapter was twofold: 1) to explore the social lives of older adults through their relationships and activities and 2) to understand how our participants learn and engage with technologies and the barriers and frictions they encounter.

In the first section, we discussed the human desire for loving companionship, touching on themes such as love, romance and dating as well as ideas around duty, trust, obligation and reciprocity with children, friends, and neighbours. Many older adults are

content to live alone, or with the companionship of a pet but this chapter also explores social and emotional forms of loneliness as major challenges of the later life course, and the fear of lack of support in times of need by socially isolated seniors. Equally we hear of community monitoring strategies involving neighbours 'keeping an eye out' and alerting children if things seem amiss, or grandchildren creating and coordinating a regular stream of social interaction via digital channels such as WhatsApp groups. Retirement for many is an opportunity to explore new interests, hobbies, and ventures. For some this involves volunteering or returning to education, either to learn or to share their experiences with others. Activities such as dance, sport, and physical exercise are popular among many participants, with some such as Robert enthusiastic about digital technologies helping set goals, track, and encourage his progress. The freedom to choose how to spend time was novel to many and appreciated by most, as was the ability to say 'no', though as we will see in the following chapters, this can be limited in many ways during the later life-course.

The second part of this chapter focused more specifically on how older adults learn and interact with digital technologies, sometimes willingly as in the case of Monica who loves her tablet and the Open University and sometimes in response of life course transformations requiring the acquisition of new skills or knowledge as in the case of Franz in Germany who had to learn to cook – first under the tutelage of his ailing wife, and then later via YouTube videos following her death. The impatience of youth was noted by participants, as were the assumptions made by 'digital natives' about the ease of 'learning by doing' with unfamiliar technologies. As one participant explained, she wants step by step instructions that can be followed like a recipe. Or alternatively as Ludwig explains 'more hands-on support'. Language too was discussed in our case studies. Accessible language that avoids unfamiliar concepts and metaphors is as important as are complete instructions in languages others than English. Motivation to adopt technologies varied greatly among our research sample and whilst some older adults were technophiles, others limited themselves to simple functions of technologies or invested time and other resources tactically in response to existing and emerging needs or family demand. Structural barriers to technology participation such as cost of hardware and poor access to broadband were also identified in some regions. Frustration, suspicion, reluctance, and a feeling of incompetence were commonly expressed by older adults struggling to acquire technical skills and access to digital worlds, as were pride and sometimes a sense of wonder at the possibilities that a smartphone or tablet opened up to them, particularly during periods of enforced isolation and lockdowns caused by the Covid-19 pandemic. Others pointed to the dangers created by technologies that make things 'too easy' or degrade skills required for self-reliance.

We end this chapter by reiterating Ted's advice for SHAPES developers, designers, and practitioners – technologies can 'be beautiful' and 'practical' but they also need to be considered within the learning contexts and social lifeworks of their older

beneficiaries as they can also be so "helpful that it can make some people feel useless, unwanted and isolated."

2.5.1 Insights and Reflections

Considerations for policymakers, solution developers, and service providers:

- Is the context surrounding solution adoption truly understood? Has proper due diligence been done to understand both the stated and unstated barriers of adoption? As observed, sometimes small and seemingly insignificant obstacles such as the lack of instructions available in people's native language, prevented or hindered the receptiveness of ideas.

- Playfulness and memories have an impact on people's willingness to engage with sports and exercise activities (e.g., FitBit watches, dancing, etc.). These motivational drivers can be translated into tools developed for physical and cognitive stimulation at home to reduce risk of falls.

- Having choices and the liberty and ability to say no to certain activities as well as the pleasure to follow one's desires was highly valued by the majority of our research participants. In what ways can social apps that offer information on activities and communication with peers in the local region help provide opportunities to choose from?

- The development of technology is often done by external professionals who apply specific criteria of perceived functionality or usefulness to an older age group. This chapter, however, suggests that we should integrate older adults' own criteria in how they assess functionality or usefulness according to their changing needs and motivations, especially after critical or disruptive moments in their life (e.g., retirement, losing a partner, getting ill, etc.).

- When developing approaches to tackling loneliness and social inclusion, it is important to think clearly about the differences between 'social' loneliness and 'emotional' loneliness.

- Have existing embedded social infrastructures such as local parishes, sports clubs, and family groups been considered in the implementation of a solution? Do the people you serve have meaningful access to these ecosystems and how could these be built into / connected to your services in a meaningful way?

MOVING THROUGH THE WORLD
Chapter 3

Chapter keywords: Mobility, Falls, Transport, Driving, Accessibility, Stairs, Wheelchair, Walking, Home, Public Space

3 MOVING THROUGH THE WORLD

Monica

Monica is a retired schoolteacher in her late 70s living by the sea in a small village in Northern Ireland, a short distance from Belfast. Although poor health and a degenerative spinal condition have stolen much of her height and mobility, her charismatic personality is undiminished. An enquiring mind and precise diction, coupled with the ability to switch at will between a cheerful disposition and a commanding manner, promises a rapid education for those who make the mistake of underestimating or patronizing her. A bus driver learned this lesson the hard way. Monica recalls struggling to board an empty bus at the start of its route with her rollator walker full of shopping. Pointing to the sticker of a wheelchair proclaiming the accessibility merits of the vehicle, Monica asked the driver to lower the ramp and was met with a curt refusal. 'That's only for wheelchairs' she was informed. After some struggle to embark she managed to get on board the bus and a stern lecture ensued.

> "I sat down in the front seat, and I told him strongly but politely what he had done wrong. Well, I said, you know, I've got two solicitors in my family, and I do know what's right and I think you're being very foolish to be so uninformed about this."

On this occasion, an apology issued from the chastened driver, but Monica has not always been so successful on public transport. In general, however, over the course of her gradual deterioration, she has found that most people are only too pleased to provide assistance as long as you make direct requests in an unembarrassed manner and treat them as if they are a favoured relative from the outset.

Monica's history with mobility aides is long and circuitous; a string of humorous tales of experiments, falls, dead batteries and burned-out motors. Her ability to manage with just a walker as an assistive aid now long passed, Monica first used a mobility scooter in England rented by her daughter. She loved it so much, her family bought and shipped the machine to her in Ireland at great expense. Having never driven a car, it was not easy to learn, especially negotiating tight areas and backing up. Her first proud adventure in it into her village ended with her trapped on the edge of a road kerb after a miscalculation over its height. The scooter died and she had to call a friend to tow her home, only occasionally bashing into the back of his car due to the lack of onboard brakes. Back home she tried to fix it, initially replacing its batteries but was informed by experts that her new scooter was beyond repair.

Undeterred by the death of her first scooter and an avid fan of eBay and other online second-hand sales websites, Monica has now compiled an enviable garage of mobility

aides. Her next scooter was smaller but sturdy. That is until she drove it down the garden where the wheels got stuck in the soft earth and tipped her into her hydrangea hedge. Her subsequent purchase was a much bigger machine with headlights and indicators. She could not believe her luck as she managed to buy it very cheaply for £600 from an older lady who moved into sheltered accommodation with rooms too small to host such a robust device. Monica also bought herself a powerful electric wheelchair with independently driven large wheels; her equivalent of a 4X4 off road vehicle so she can join her daughter on long hikes and countryside walks. This has carried her up steep hills and rocky pathways in forests and sites such as Giant's Causeway, but she learned the hard way not to use it in the city. Uneven pavements with kerbs send the wheels in different directions and steering becomes difficult, dangerous with so many people around. People reading their mobile phones, inattentive to their surroundings, walk into the back of the chair or force her to suddenly brake, risking injury to all.

> "I thought, oh, my God. I'm not going to drive a wheelchair in the city again. It's much easier on a mobility scooter if you are going through a crowd of people. At least I have found that because you have got the small driving part in front of you, the bit that comes up. A bit of metal and something to hold onto. Whereas in a wheelchair you are exposed."

Navigating other forms of public transport rarely causes Monica trouble, although she notes that small train stops or 'halts' without proper stations can be very difficult to traverse in Northern Ireland. Trains are usually well setup for people with wheelchairs and the staff tend to be accommodating and well trained. The secret she explains is to always do your research on the internet or even better call ahead on the telephone and alert them to your times and points on your journey.

A keen traveller, Monica has always enjoyed travelling on planes and argues that no one disabled should worry about going through airports. Trips to visit her children in Europe, the Middle East and Australia has given her extensive experience negotiating assistance to the gate. The support and attention can vary according to how busy the staff are, but she always has "a bit of craic with the people pushing her" and suggests that "I never feel that I'm sort of like a weak invalid or anything silly. No, I don't feel that way." Eager to help others, Monica wants it to be widely known that it is free to take wheelchairs or scooters on planes.

> "I've travelled by plane a lot since I have been really unable to walk very far, and the airports are wonderful. They put my vehicle in the hold and bring the batteries in with the pilot… you can ride your wheelchair to the foot of the steps in the UK and you can wait for the steps. If you can't walk at all, they'll take you in another wheelchair in a lift up to the cabin, and they don't want you to sit in your own wheelchair in the plane even if it's booked for you. I suppose it would block the way."

Now grounded by COVID-19, Monica is avoiding planes, trains, and buses alike, keeping herself busy with reading, writing, her garden, her much loved tablet, and a few close friends and carers.

3.1 Introduction

Monica's account above is rich with insights about the gradual adoption of mobility aides and technologies as well as their limitations in different environments from crowded city streets to airports, buses and steep Irish hillsides. It illustrates the difficulties involved in learning to use new devices as well as the accidents and unexpected costs that can accrue. Her story also points to strategies for coping with the frictions of multimodal travel and navigating public spaces for less able-bodied persons. Most important though perhaps is the message from Monica that barriers to accessibility are not just structural such as a lack of transport options, poorly designed and neglected environments, or inadequate technologies, but also social and educational. Through her eyes and embodied experience, we are alerted to the consequences of untrained personnel, inattentive drivers, and busy crowds, but we also learn about the value of well-planned, carefully executed service delivery, and reminded of the importance of manners and consideration.

This chapter begins with an exploration of experiences of older adults moving within their homes. This includes barriers created by the physical domestic environment, established and creative coping strategies, and the consequences of falls in the home. The second part of this chapter concentrates on the challenges older adults face navigating public spaces and systems, and the journeys our research participants make both spatially and temporally through the life course as they reflect upon and sometimes adapt their travel preferences, practices, and reframe their capabilities.

3.2 Negotiating Home as an Index of Mobility

Beyond its obvious function as a shelter, 'home' was variously portrayed by our participants in positive terms as a 'refuge', 'my little corner', a site of stored and shared memory, a network of relationships, a sense of enduring stability, and a profound attachment to place, both private and communal. A preference for remaining in the home as long as possible was expressed by most interviewees though awareness of challenges for coping in difficult circumstances and the potential for lack of independence was exacerbated by the restrictions and limitations of the coronavirus pandemic. Many of these challenges are explored in later sections of this report, but this segment will outline some of the key aspects of the physical relationship between the home and the changing bodies of its occupants as they traverse the later life course.

How a house is laid out and arranged can pose multiple problems for older adults with physical disabilities and the (in)ability to manage, overcome or circumvent barriers in

the home can frequently contribute to how self-efficacy is perceived. Successful management of the embodied challenges of negotiating everyday living in one's home is a powerful and sometimes painful measure for how many older adults assess their ability to live independently and reflect upon their personal mobility. Often these involve extrinsic changes to the domestic environment and sometimes these are imagined by older adults as potential challenges to be intrinsically assessed, measured, and hopefully defeated.

Julie, an 87-year-old widow living alone in an apartment in Czechia is generally very happy with her living arrangements. Her apartment is very comfortable, and she feels it has a 'beautiful loneliness'. She is content in her own company and takes satisfaction that everything in the flat belongs to her. She especially enjoys not having to share a bathroom with anyone. Before she moved in, her daughter helped prepare the apartment and make it 'barrier free', something they were well prepared to think through in advance as Julie's husband had used a wheelchair before he died. Nowadays, Julie herself uses a walker at home and notes that when it is bad weather outside, the size and layout of her apartment allows her to open all the doors into a circuit 'just to walk'.

The greatest challenge for Julie was outside her immediate control and responsibility. She explains,

> "The entrance door to the house was a big problem for me, because it is heavy and I am stuck with these two crutches … the door closes itself, or I can open it all the way and block there. But because of my carpal [tunnel syndrome], I no longer have a feeling or strength in my hands, and that door just makes me a big problem."

When Julie is out with her daughter, her daughter gets out of her car and goes to open it for her, but when she is alone, Julie often struggles to handle the weight of the door and has in the past been locked outside for a period of time. Many of the residents in the seven-storey apartment block now know her and will stop to help. The local children also keep an eye out for her, "those in the range of 13, 14, 15 years, as they see me coming with those crutches, they're waiting for me to let me come in and they will not close the door under my nose."

The problems caused by doors range from weight to inadequate width to difficulty managing them whilst holding other objects. Our participants described how they individually adapted to everyday challenges and created home-grown solutions to tackling these such as walkers semi-closed and balanced whilst navigating narrow doorways and corridors; moving frequently used items away from hard-to-reach cupboards; and wheeled trollies used to move around heavy objects. Polly in Northern Ireland purchased an old tea trolley for eating her dinner in front of the television and helping her move the heavy dishes back and forth from her living room to the kitchen.

In the last year, this device has quickly been put to work as a solution to an emergent need as she began to experience severe back pains. One consequence of her weakened state is a difficulty holding open the fridge door whilst leaning in to rummage through its contents. She now wheels the trolley over to block the door and provide a surface to temporarily place and transport the items she selects. The same trolley has helped solve Polly's problem of watering the many plants in her front garden with no tap available close to hand. As she no longer has the strength to haul buckets of water, Polly repurposes several two-litre plastic milk bottles filled with water and transports them on her trolley to her front door.

Stories about the obstacles created by stairs are interwoven through many of our case studies. Even physically fit and active older adults discussed the strain that walking up and down steps caused their knees. Xenia (66), a retired cook, florist and restaurant owner in Germany who advocates for female entrepreneurship, found struggling with her knee problems deeply challenging, describing that when you are immobilised you feel so old and disconnected. These challenges were particularly acute for participants such as Danae, aged 69 in Greece who is obese, a smoker and suffers from respiratory problems.

> "Yes, it is really difficult for me. If I had the choice to only live in the basement, I would never go upstairs again. I can't do this anymore. I used to go up the stairs very quickly 20 times per day, I wonder how I could do that. My mother couldn't go up the stairs. Imagine, we didn't even have a handrail for the stairs, and I decided to have one in order for my mum to manage to go up the stairs. Now, we have handrails in each side, and I can't even go up the stairs at all. If I don't hold the handrails, I will go very slowly, step by step."

Danae's preferred solution – if she had the financial means – would be to install a downstairs bathroom. This desire was also evident amongst other participants who expressed frustration when personal or public funding was not forthcoming to help fit convenient or accessible ablutionary accommodations.

For Frau Blume (aged 80) in Dresden, stairs offer both an opportunity and a challenge. Currently she is physically and mentally fit, and says she enjoys the stairs in her split-level apartment as a form of exercise. Her flat is not wheelchair accessible however and to get to the first floor she would have to walk. She feels that if she lost her ability to walk easily, she would be forced to move and has pre-arranged a retirement residency near her daughter's house should this ever become necessary. Gisella (79) and her husband in Italy made a similar move to a ground floor flat fifteen years ago when chronic bronchitis made it increasingly difficult to take the stairs. Like a great many of our participants, underlying such decisions is a fear of deteriorating to a point that they become a 'burden' to their loved ones.

Evelin (aged 80) living in Germany recalls the decision to move house with her husband from the mountainous location in which they lived after a series of attempts to adapt to his failing health needs. They lived in a house with a large garden and because of the hilly location there were steps everywhere. She counted 20 steps just up to their house through their garden and notes 'that gets harder as you get older'. Maintaining the garden without her husband's help was a struggle. Evelin's husband used to like to walk into town but over time the climb back up the mountain, followed by the garden steps became too much for him. At first, he would take a rest every few minutes and pretend to look at the scenery as he was embarrassed about what people would think. The neighbours were understanding.

> "One family even had a chair that they didn't need anymore. They painted it nice and colourful in blue. They put it in front of their door. They said, 'if the gentleman comes up here and is exhausted, then he can sit on the chair, then he has already done half of the mountain'."

The time came when walking was no longer possible and so Evelin would drive him up and down in the car. Eventually however, her husband's heart problems reached a point when they realised that they could no longer cope so they sold the house and moved to a more convenient location.

The choice of relocating to more convenient accommodation to meet changing mobility needs is not always feasible. This may stem from a reluctance to leave behind memories, friends, family, and neighbours but financial constraints also play an important role for many. Mike (77) in Dresden is one such example. He suffers from asthma and high blood pressure but is otherwise fit and active. He and his wife live in a beautiful fourth floor flat in the city which they greatly enjoy but the lack of an elevator in the apartment complex means that they rarely have visitors anymore and they are both starting to find the stairs challenging. They are keen to find a more suitable apartment in the same part of Dresden but whilst they have a pension sufficient to suit their needs, they cannot afford the high rents asked for today.

Stairlifts, handrails and grab bars where fitted, provide a partial solution to the difficult issues of traversing steps. Charlotte (67) living near Cologne spoke of the difficulties in managing staircases in homes and public places with only one side handrails. Using a walking stick, she often finds herself troubled by wrong sided placement. Formal assistive aids were often complemented by creative solutions devised by participants. Participants describe how Zimmer frames and walkers would be placed both at the top and bottom of staircases. Walking sticks 'live' in all corners of a room or in strategic locations along the course of well-trodden pathways. Furniture is also often rearranged or positioned in such ways to allow clear spaces for movement whilst a carefully placed or chosen chair back, table, shelf or wall provide essential support and opportunities for balance and rest.

Danae has tried numerous diets to lose weight but attributes her lack of progress to insufficient exercise due to her fear of falls. The lack of confidence imbued by a serious fall or series of balance related accidents is another major theme in our data. This was particularly striking in the account of Bert, aged 70, who lives in a semi-detached house in Northern Ireland. For much of his life, Bert has been a heavy smoker and drinker, but this got much worse following his second divorce and when he retired and lost his daily routines. He had a stroke that left him very unbalanced, and he still feels he slurs a little. Even after his stroke he continued to drink a bottle of vodka a day until a year ago when he experienced a very bad fall that left him lying on the floor of his living room without food, water, or heat for three days. He had left his mobile phone charging upstairs out of reach and to that point had resisted wearing an alarm pendant because of the stigma associated with it. His left leg gave way and Bert didn't have the bodily strength to pull himself up. He managed to pull a blanket off the sofa and wrapped himself in that and recalls how nobody called or came around. "I lost count of how many times I wet myself." After three days, he knew he was close to death and vaguely recalls slowly inching his way into his hallway acquiring severe carpet burns on the way to his landline telephone where he managed to call 999. Since this episode, Bert has given up alcohol and has invested heavily in assistive devices. He has very little personal mobility at present and is largely housebound. He manages around his house with a Zimmer frame, rollator as well as a stair lift that he paid to have installed rather than wait three months living in his front room until the NHS could provide one. He is considering purchasing a mobility scooter for outdoor use but is put off by the cost. On his birthday, he decided to trade in his manual transmission car for an automatic car but has only driven it once after feeling a burst of panic driving to the shops and asked his daughter to take on his car for a while.

3.3 Navigating the World Outside the Home

Monica's vignette at the beginning of this chapter is rich in detail about how she manages to traverse the world outside her home, despite a deteriorating back condition, ill-tempered bus drivers, city crowds, and high roadside kerbs. In her longer case study, Monica also provides valuable insight into many other difficulties faced. Finding accessible toilets is high on this list and Monica gets quite angry about how toilets designed for disabled people are frequently used by others or are out of order. This had very dramatic consequences for her personally. Monica carefully pre-plans all her journeys and this includes building an awareness of where she can empty her bladder. During one trip to a supermarket, Monica found her usual 'pit stop' out of order and after enquiring about an alternative was escorted to a staff bathroom. Unfortunately, without handrails to help her, Monica fell over sideways trying to pull down her trousers and banged her back on the toilet base, quite severely injuring herself. Several years later, after legal action she received £24,000 in compensation.

Closed facilities such as accessible toilets are only one of the dangers of navigating public spaces described by our research participants. Sometimes these are merely

inconvenient such as the removal of many benches and public seating in communal spaces or 'takeout' only options in coffee shops during the coronavirus pandemic. Much like the furniture 'surfing' or 'cruising' activities outlined above within the home environment, the phenomenon of pre-planning resting points along their trips is well described in several of our interviews. Sometimes these dangers are more serious with implications for both access and physical health. Cluttered or poorly designed streetscapes, with badly parked vehicles, inadequate signage, uneven and broken pavements all cause great difficulties for persons with impaired mobility. Seasonality of course also plays a role here as Helena in Czechia reminds us. Even though she has no need for walking assistance and tries to stay active by venturing to meet friends every day, Helena finds herself scared of going out during wintertime because of the slippery pavements and increased risk of falling. Earlier we mentioned Polly's proactive and often creative solutions to challenges in her home. Her instrumental problem-solving capabilities extend to the public environments around her. Having suffered a broken wrist from a fall caused by a badly installed manhole cover, Polly successfully prosecuted the water and road authorities involved. She has subsequently surveyed and made complaints of five raised and uneven manholes in her town as well as a standpipe water leak causing a sheet ice patch on the street. These have all been quickly fixed following her intervention.

In the warmer climate of Gran Canaria, Alegría (72) is a white and red cane user. This is specific to persons with deaf blindness. She gradually lost her vision in her 30s and is now almost completely blind but hears well enough if there is no background noise and is spoken to loudly, slowly, and clearly. During the coronavirus pandemic, face masks and plastic barriers found on counters and in shops have worsened communication. She explains that the main barriers she encounters in the street are scooters, bikes, and cars badly parked. She uses a device that activates the sound of traffic lights to indicate when she can cross safely, but after a new bicycle lane was created near her house, the traffic lights were changed, and the device no longer works. As a result, Alegría can no longer cross the road outside her home independently. She has lobbied to have this reinstalled but because some of the neighbours had complained about the noise of the tool, this has been used an excuse not to rectify the situation. The safety of older pedestrians at crossing points on road intersections has long been a concern within the gerontological literature. A study by researchers at the Technology Research for Independent Living Centre compared standard times for pedestrian lights in Dublin with age and walking speed and concluded that standard crossing times appeared insufficient for older adults over the age of 80 (Romero-Ortuno et al, 2010). The need for adequate infrastructure and services is also strongly argued by Achilleas (aged 65), a wheelchair user since a mine accident crushed him at the age of 26. He explains:

> "I think the most important thing is access. It is important to have the conditions to be able to move. This gives you autonomy and independence. Transportation from the house to the sidewalk should be ensured. The

sidewalks should be spacious and without obstacles and have ramps with a suitable slope at the end, not only in the city centre but also in the neighbourhoods. All public transport must be accessible. Planes and trains have better accessibility than intercity buses. Furthermore, accessibility should not only be in public buildings but also public assembly buildings such as theatres, banks, cinemas, and museums so that everyone can have their needs served."

Achilleas further notes that many of the most accessible hotels are expensive whilst others frequently misrepresent how accessible they actually are. He stresses that it is important for service personnel and the public to be aware of the needs of those with disabilities. Like Monica, he vividly remembers a rude bus driver angry at having to assist him. Others complained about starting and stopping speeds on buses as well as the dangers posed by steep bus stairs. At the age of 87, Julie in Czechia is unable to walk without mobility aids and nowadays finds public transport too challenging to use. If her daughters are not available to drive her to hospital appointments, she uses a taxi service. This option facilitates door-to-door transportation for older people with the added benefit of removing the additional challenges of the journey from the home to the bus stop or train station. Furthermore, for those who seek it, taxis and services such as Uber can also create a possibility for assistance carrying objects such as shopping bags, or on occasion, providing a helpful arm to lean on. On the downside, waiting times and sufficient availability of taxi provision were cited as challenges. Booking in advance is common, but the use of real time taxi location apps was not yet prevalent practice among our participants. This may change as many of the coronavirus lockdown measures lift.

Mike (77) in Dresden mentioned in the previous section, is frequently critical of aspects of online life, especially the constant advertisements that annoy him on his smartphone, but he finds himself increasingly utilising the digital tools at his disposal from telebanking, telemedicine, the Google search engine, and online shopping from Amazon to holiday bookings. He explains,

> "Many things are easy - especially holiday planning. I already said, we plan everything ourselves. Without the internet, it's difficult. It's much easier that way. Or tickets for trips. But I know many of my generation who suffer from this and when I say, 'why don't you take the train?' they don't know how to do it because they can't buy a ticket. There is no train station in their town, and they don't know that you can do it through the internet. You have to get used to everything and learn the ropes. Then it works. But it takes a long time. You also get slower [laughs]."

Also in Dresden, rising rent costs and an – in her opinion – needlessly large apartment in the centre of town following a divorce, led Hannelore (76) to suffer through an ordeal moving to a new apartment in a still little developed area; a time she remembered as

the most difficult and lonely years of her life. Now she lives in a small, publicly well-connected village just outside Dresden. She adores the area, which has all amenities within walking or cycling distance and where green areas and a golf course allow for extended walks and recreation. Hannelore makes transportation decisions based on her needs, the seasonal conditions, light levels, and perceived safety. Public transport is good, although, as she says, going to Dresden for evening events or in winter, she prefers to take the car as she would otherwise have to leave town early to catch the last tram home or cross secluded park-areas, something she would be afraid to do as an older woman on her own.

> "So here in our area, when I go shopping and get something, I do that by car, of course. And when I go into town – in our case, town means Dresden – I usually drive to the tram stop. That's four kilometres, and sometimes in the summer I've also cycled there, but if it's too warm and you arrive sweaty, that's no good either. And then I leave the car there and take the tram into town. Not because I'm afraid of the traffic, but because of the parking spaces. It's getting harder and harder to find parking spaces in the city. I find it more relaxing to take the tram. Except when there's a concert or a visit in the evening, when I'm out and about, I don't use public transport. I've grown tired of it since all kinds of robberies and very unpleasant situations have happened on public transport, and I don't like standing at the stop for a long time in the evening waiting for the tram. So, in the evening, when I have plans, I generally go by car. And otherwise, I like to use Dresden's public transport. They are quite reliable and well organised."

Cycling was a common activity among many of our participants, as a hobby, a form of exercise and a means of locomotion, especially in Germany, Portugal, and Greece. Nikolas (aged 84) in Greece identified two measures of mobility that he is determined to prolong for as long as possible: taking care of his garden and to keep riding his bicycle, which he loves because it makes him feel free, much like when he was a small child. Bicycles can also provide greater ease of access to local neighbourhoods than driving. The problems of finding parking spaces are well known to urban dwellers of all ages, as Hannelore describes above, preferring to 'park and ride' at a tram stop. Achilleas says, "it is not uncommon for me to have to return home because I could not find a parking space in the city centre" and advocates that quality of life for many disabled people would be improved by a reliable mapping platform or application where the locations of parking spaces for the disabled are recorded and that will inform them if they are occupied, or if they are occupied by non-beneficiaries.

Driving practices frequently change and adapt in the later life-course, sometimes as a result of deteriorating eyesight, physiological or cognitive abilities, the cost of running a car, or a lack of self-confidence. Some older drivers comment on increasingly heavy traffic and aggressiveness of other road users, and others, like Bert, worry they no longer have the skills or reaction times to drive safely without causing an accident.

Some stop entirely and others begin to limit their journeys to familiar routes or adapting their agendas to travel during quiet times of the day or avoiding difficult poor light or weather conditions. Loss of access to a car can be devastating to many older people, especially in rural areas with limited public transportation availability as pointed out by Suzanne in Germany who at the age of 85 feels she cannot bear the idea of downsizing, sorting through her possessions and relocating to an area better served by public transport. With her ability to walk decreasing, her car is essential to get her and her mobility aid into the city, where she can go "from shop to shop with the rollator, i.e., to the pharmacy and the doctor and whatever I have to do."

The restrictions of the coronavirus pandemic have had many consequences for older adults. Giuliana (84) in Italy explains that she gave up driving because of her advancing age and began to use buses instead. At the time of her final interview with us, she had been "at home without moving for three months". Her son and his partners did all her grocery shopping and took care of all the necessities. She is now starting to venture outside the boundaries of her home once more by foot but avoids public transport at the request of her children. Having been inactive for such a prolonged period, Giuliana is struggling to regain her agility and fitness.

> "So, my problem was that, not having moved my legs for so much time, I struggled a lot moving them again after that period, I'm having problems now walking, I walk for a short time and then… but it's hard, you know. I'm getting prepared now to begin rehabilitation doing water gym as I did last year, because my sciatic nerve hurts. I did it last year and it felt well, I haven't done it this year yet, because I had to do some medical exams before. I'm going to go to the orthopaedic this Monday and then I will begin with this rehabilitation somehow, because the sciatic nerve is very debilitating."

3.4 Conclusions

The diverse accounts of the older adults in the 90 households of our research study offer numerous rich insights about barriers, challenges, and strategies for moving within and between domestic and community environments. Key themes that have emerged include a strong desire for the majority of our participants to keep living in their own homes for as long as possible, balanced with an acceptance of the challenges that many such environments create for successful 'ageing-in-place' and maintenance of a life of independence and quality. The relationship between the body and how the home is physically laid out is explored here, with examples provided of barriers created by stairs, doors, corridors, bathrooms, and gardens. Furthermore, it is explored how technological and non-technological aids are utilised and sometimes creatively innovated by older adults to solve emerging and recurrent mobility problems. Added difficulties of mobility and navigating in the home appear when such physical challenges are worsened by cognitive decline and the anguish of losing

control over organisational skills, bodily functions, and mental capabilities. These challenges are discussed in Chapter 6, Informal Care and especially 6.2 and 6.2.1.

The causes and consequences of falls is another key theme within this chapter, spanning both the home and the dangers of poorly designed or managed urban environments. Some of the limits and constraints placed on the lives of people with mobility difficulties are outlined. These include issues with parking, driving, walking, using public transport, streetscapes, resting and anchor points, roads and pedestrian crossings, and are considered in relation to how and in what ways do these affect perceptions of capability, self-efficacy and decision-making around mobility pathways and choices.

3.4.1 Insights and Reflections

Considerations for policymakers, solution developers, and service providers:

- This chapter demonstrates that moving around is a complex activity that involves different phases ranging from leaving the house, getting to the first transportation hub, getting on and off transportation, and arriving at a destination. Further rest points, speed and emergency scenarios have to be considered. Very often policymakers solve one phase, or aspect, for example making a bus accessible for wheelchair users, but if the bus stop is not accessible the barriers are not solved. Planning should therefore consider the whole journey and its challenges and if multiple planners or services are involved, they should liaise with one another.

- What can be done to improve infrastructures, tools, and service solutions to strengthen older adults' confidence in moving around independently and safely? Could service providers utilise this report's insights to amplify or support people's creative workarounds to everyday problems?

- Given the obstacles highlighted in some of the stories in this chapter, are there ways that everyday people and service staff can be empowered to be aware of the mobility and accessibility needs of others? Beyond the physical, observable, limiting forces of inaccessible infrastructure, what can be done to reduce/ remove social norms and expectations that play a role in disabling a physically challenged person?

- What practices could be implemented to factor in the opportunity cost of solutions? For example, is it more cost-effective for a state to provide someone with financial support to implement a downstairs toilet, extending their ability to remain in their own home, or cover supporting costs for a room in a nursing home?

WORKING WORLDS
Chapter 4

Chapter keywords: Employment, Work, Volunteering, Chores, Division of Labour, Housework, Shopping, Participation

4 WORKING WORLDS

Hugo

Hugo, aged 77, lives with his second wife, a secondary school English Teacher, in a house in the centre of Aveiro in Portugal. He has one child, a 24-year-old son who is studying Engineering at the University of Lisbon. Working since he was 18, Hugo has seen employment in numerous occupations during his lifetime: civil construction worker, topographer, factory director, architect, urban planner, and professor in a Portuguese university. Although he is officially retired with a pension, Hugo still designs some architecture projects, which he seems to find satisfying and fulfilling. He also values his time. At the start of our research engagement, Hugo set clear ground rules and explained that:

> "I'm ready to collaborate with you in whatever way is possible, as long as it is kept in the commitment of time, because for good or for bad, I still work, okay?"

Hugo is an active, resilient, optimistic, and enthusiastic older adult. He enjoys several hobbies such as sailing, walking two kilometres a day in the city, riding his bicycle, drawing, painting, reading, listening to music, and studying architecture. Hugo talked a lot about political and social aspects of the pandemic and from his life. He lived in Oxford following his university graduation and worked in Amsterdam and Italy. He loves travelling in the company of his wife. They have travelled through the United States and in many countries in Europe, but what he really remembers with nostalgia are the summer holidays he used to spend with his wife and son in north Portugal, fondly reminiscing how they used to build footbridges to cross streams. In addition to such trips, he usually spends holidays such as Easter and New Year's abroad.

Hugo recalled his childhood and the problems that he and his family faced due to their difficult economic circumstances as well as the challenging political situation in Portugal at that time. Hugo's parents lived in an isolated location near to the sea and he used to go by speedboat to São Jacinto, which was the only place where there was a teacher capable of preparing students for admission to secondary school. Because the place they lived in was very remote, the first 14 years of his life were very hard. He remembers how when his father felt ill, Hugo had to cycle a long distance to the only doctor in the area. There, he had to describe his father's symptoms to secure a prescription and then travel to the city to buy medication. He also recalls that during those years, sometimes the three of them had to divide one sardine for their dinner. Hugo regrets that he lived in a place devoid of children of either sex of his age, and how his social life and development were limited by playing alone until he went to school.

Acknowledging the influence of politics during his later youth, Hugo was an active citizen during the pre-25 April Revolution, being part of the Democratic Opposition. His commitment to political engagement continues to this day. Seventeen years ago, Hugo founded an informal think-tank for reflection and intervention on city issues that he still coordinates. This has around 180 members, including many influential figures such as public personalities, university staff, and politicians.

Hugo has a positive attitude towards technology and uses it daily, most frequently for his Architecture and Urban Planning projects, but also to produce opinion articles, manifests, public statements, and communication within his civic think-tank. Nowadays, due to the pandemic, Hugo usually speaks with his work colleagues using a videocall app. He also uses it to meet monthly with the members of the civic think-tank and record the meetings. Hugo manages a blog to share with civil society the outputs of his group and publishes in local and national journals and the radio.

During one of his earlier careers as a factory manager, Hugo suffered from a breakdown caused by overwork and exhaustion. Consequently, he learned how to compartmentalise his time, protecting his private and family time; a practice he maintains in retirement. From Tuesday to Friday every week he works on professional projects, with Wednesday always dedicated to civic matters. Weekends are reserved for family, and Mondays are set aside for himself.

4.1 Introduction

In the previous chapter, we explored some of the ways in which many older people work to access, navigate, and manage their domestic and public environments. Much like the creative solutions and practical planning outlined, Hugo's story is packed with insights that contrast against popular narratives that situate older adults as passive, lacking agency or non-contributing. Instead, he begins by noting that he is willing to participate in our study but also establishes how busy he is. He continues to accept occasional commissioned paid work as an architect, including projects with overseas clients, but his passion and time is also consumed by active engagement with civic and city issues in Aveiro and further afield. His energies are placed into managing a sizable voluntary organisation and informing the public through social and traditional media channels. His schedule is carefully planned and managed to ensure he can balance his family and personal needs with his professional and voluntary projects. Most importantly, Hugo reminds us of the diverse contributions that older adults can and do make to their societies and communities and points to the "many abilities, many skills, many ideas not used in our country" with those in "the Third Age" particularly prone to "abandonment".

This chapter aims to share insights from older adults across Europe about some of the forms of work and labour involved in the later life course. Three domains are covered here: 1) the everyday work of managing domestic life 2) contributions to civil

society through volunteering and active participation and 3) paid labour. It is advised that this material is read in conjunction with chapters 5 (Financial Worlds) and 6 (Informal Care Worlds) which deal with related themes of financial management and informal care work.

4.2 The Everyday Work of Managing Domestic Life

According to Eurostat (2021), in Europe in 2020 only 18.5% of older adults lived in 'other' types of households such as residential homes or the houses of family members. 50.1% of the European population aged 65 or over live in a household with their partner, and 31.4% of older adults live alone. There is of course, an important gender dimension to this. In 2018 the share of older women living alone was 40% in comparison to older men at 22%.

Countries involved in SHAPES pilots with the lowest numbers of older adults living in single occupancy accommodation include Portugal (21.2%), Cyprus (21.9%), and Spain (24%). In contrast Sweden, France, and Finland all have more than 35% of their 65+ populations living alone. Germany, Czechia, Ireland, and Greece have between 30-35% of their older adults in single person residences. Northern European countries have the greatest percentage of 'Couple Only' households whereas Spain, Portugal, Cyprus, and Italy all have more than 20% of 'other types of households'.

Elderly population (65 years and over) by type of household, 2020

(as % of the population aged 65 and over)
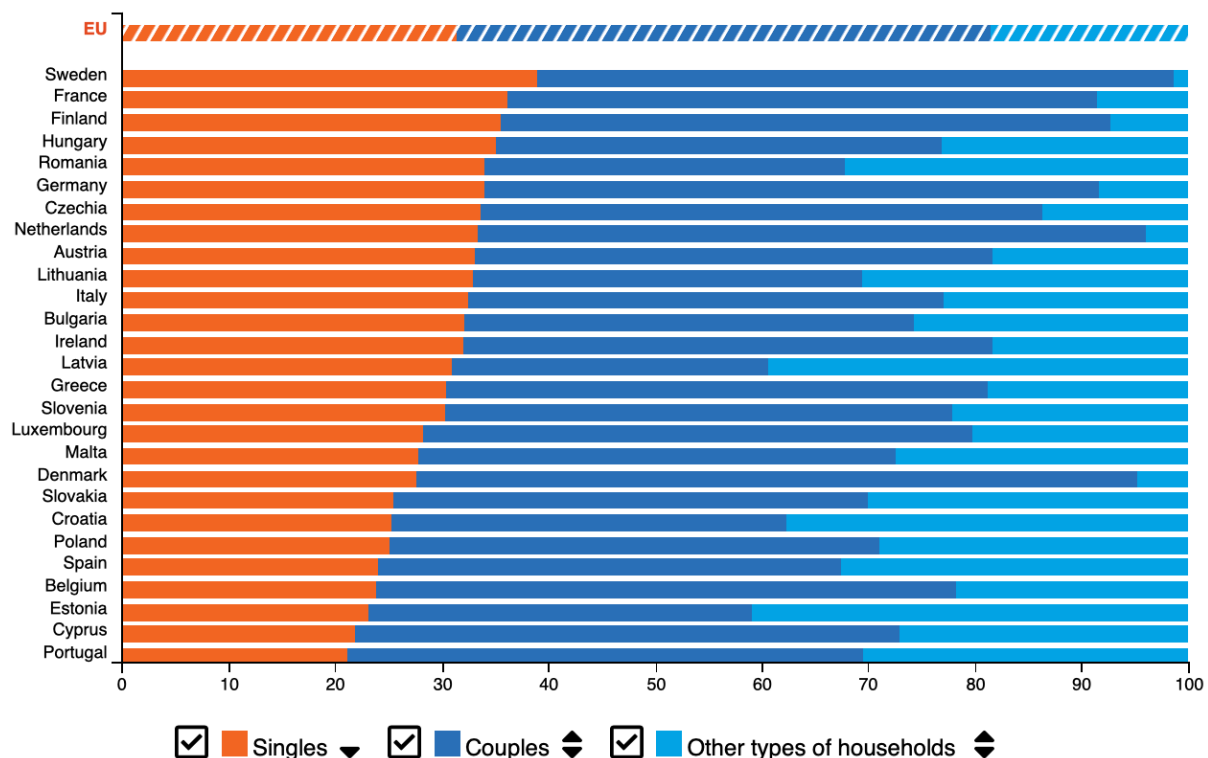
Figure 1 Older adult population by type of household, 2020. (Source: Eurostat 2021)

Task 2.1 has not attempted to replicate these figures through representative sampling techniques but rather we have relied on recruitment from local pilot partners, consortium members and, where necessary, snowballing methods. Our explicit focus has been on recruiting community dwelling older adults and only two participants residing in institutional settings were included in the sample. Of the 94 finalised case studies gathered within our qualitative research, 39.8% were older adults living alone which is significantly higher than the EU average whereas our 'living with partner only' category was marginally lower at 46.2% as was our 'other types of households' at approximately 14% of our sample in comparison to the EU average of 18.5%.
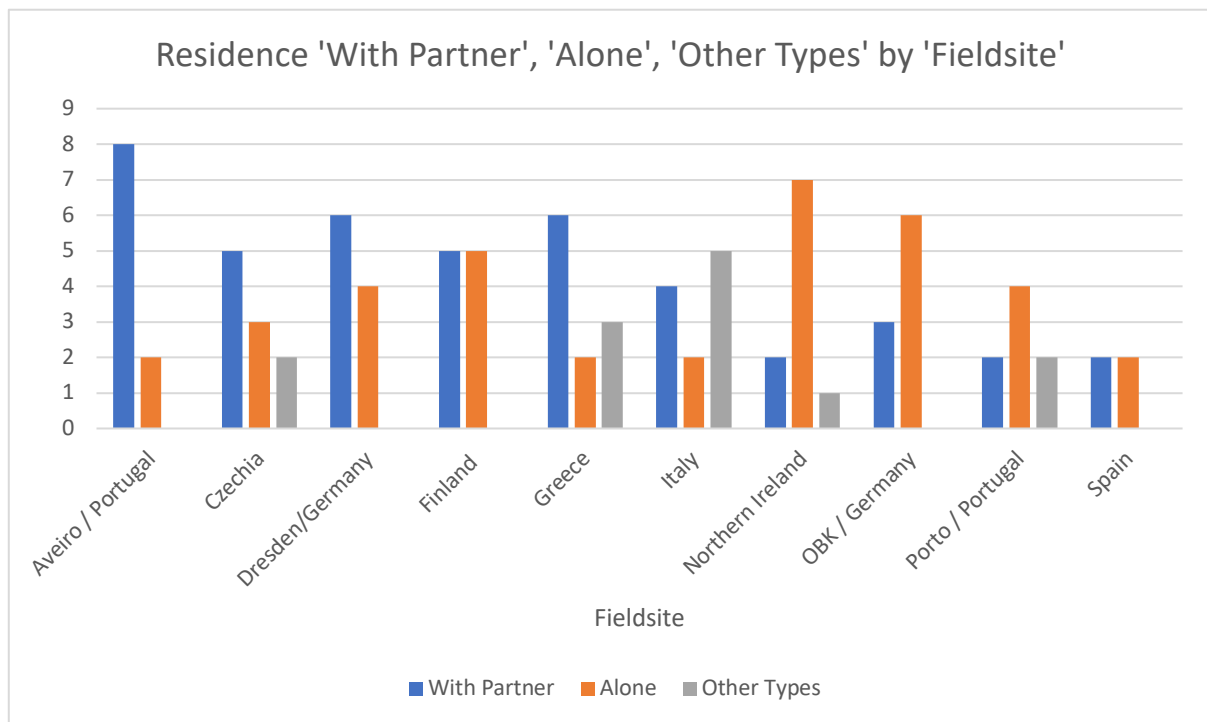
Figure 2 Chart of types of residence according to each fieldsite in this study.

In our own field sites, the highest proportion of older adults interviewed living alone were in Northern Ireland, Finland and the Oberbergische Kreis region in Germany whereas Italy and Greece had the highest proportion of older adults living in households with family members or friends other than their partners.

These patterns are partially explained by access to private or state resources and local expectations and norms about co-residency in old age, but also reflect the discrepancies in average age of participants across our field sites. Northern Ireland for example has the highest proportion of older adults living alone in our sample and is also has the highest average age at 80.2 years. Our Portugal, Greece, and Czechia field sites all have relatively young participants with average ages below 74 years.

For those living in partner only households, familiar patterns and routines for dividing household labour tasks set in earlier stages of the life course often continue for a period into retirement. For example, Gisella, a 79-year-old Italian woman moved into a ground floor downtown apartment with her husband after 15 years of marriage. They chose this location because they wished for a place future-proofed against barriers such as stairs while having access to a garden which she loves. Gisella worked in many jobs but finished her career as a photographer. Nowadays she spends most of her time at home with her husband. She doesn't have many friends nor feels she knows the neighbours well but says she regularly sees her daughter and is not particularly lonely. The division of labour in Gisella's household reflects gender roles well established during their earlier working lives, with Gisella responsible for the cooking, cleaning, and laundry while her husband takes care of tasks involving bureaucratic work such as bills and banking. She explains,

> "Yes, my husband takes care of all these things also because they are very boring [laughs]. So, I've always let him do them. When I worked, I also used to have less time, I would have time now, but he is already used to do those things and I let him do them, because I really don't… I don't want to."

Inertia created by routines is coupled with an awareness of potential resistance of her partner to negotiating new ways of dividing up chores. Gisella has always enjoyed cooking "but now I begin to be a little fed up with it, but I obviously continue doing it, because my husband would not". Tasks she has always intensely disliked include dusting and ironing. Ironing clothes now gives her backache, so she has reached a stage where she has hired another woman to come and help with this. She and her husband both love their garden and worked together to plant it. Now it is established however, the daily work of maintaining the garden falls to her.

Penelope (78) in Greece echoes statements made by several of our participants when she states, "Marriage wasn't good for me, it was a punishment!" Forced to work hard all her life counterbalancing her husband's lack of financial and emotional support in the family, Penelope continues to be responsible for all the chores in their household, although her son now helps with grocery shopping due to the pandemic. Her husband managed control over money and did all the shopping for items such as clothes "even my underwear!" Penelope also has the work of caring for her husband who is now suffering from dementia. Penelope recalls how her husband used to go out with his friends to bars whilst she remained at home with their children. "When the kids were little, I told myself that once they grow up, I will go wherever I want." Now, as she has reached the age at which she thought she would be free to have fun, she finds that:

> "I like sitting at home, I don't go anywhere, I don't get out much but where would I go? Every morning I wake up, I cook, I do housework, I iron, I do laundry. In the evening I go into my room, and I read prayers, I also read books about

saints. I have many similar books and every evening I read them. Before coronavirus I used to baby-sit my grandchild, he is 7 years old."

The theme of sharing domestic workload emerged during many interviews. Daniele, a 66-year-old divorced Italian man who moved in with his 90-year-old aunt explains that he would like to do more to help with the household tasks, but that it is not always easy to help her, because she resists his efforts, arguing that men should not do housework and that she does not wish to feel less autonomous. In Dresden, Robert (79) reflects how the experience of growing up in poverty with his divorced mother following World War II shaped his attitudes to life. Critical of what he sees as an unfair distribution of labour in almost all German households with women expected to carry a much greater workload, he explains, "I don't know if I wanted to imitate my mother or what. But the caring role suited me." He has always enjoyed tasks such as cooking, baking, shopping, looking after the children, clearing up after meals, whereas his wife took the lead on doing the laundry, car repairs and home maintenance work such as wallpapering. This said, he wishes to acknowledge,

> "I don't want to pretend I'm already a super modern husband doing equal shares. She works probably half to three quarters of an hour longer than me every day."

For some couples, a critical life event such as an accident led to a redistribution of domestic roles such as Christos (69) in Greece who first started to take on many more household chores 22 years ago after his son had a serious car accident.

> "I do a lot of the household chores. No one believes that I clear the table. I removed trash and I take care of the yard. Ok, I don't do the laundry, but if I have to do it, I will. I like helping because my wife is so tired, let's face it. She took care of my father, my mother and our son and I was working. Since our son had the accident, I started helping with household chores. Because before I had three clothes washing machines at home. I had the electric washing machine, my wife and my mother, they were like washing machines. Now I'm helping even more."

Nikolas (84) also in Greece notes how he helps with housework, shopping, paying bills, and picking up prescriptions from the pharmacy after his wife's stroke whilst Ivo (81) in Porto also began to do more around the household after his wife became ill and he had to stop the cleaner coming around during the coronavirus pandemic. Ivo is keen to clarify however, that he does not consider himself to be 'helping' his wife.

> "We divided up the tasks, that thing [saying] 'He helps me a lot at home' I don't like to help anyone … I do or I don't do [something]. My wife is not my slave or my maid. We make the beds every day, of course I put on a few kilos. I started making dishes. I would go online and look at dishes. I learnt to cook, I learnt to know the importance, well I already knew that … the importance of cleaning.

We must respect the cleaning people, without cleaning we can't live … people don't realise that?"

For those living alone, the tasks and time involved in running a household can be substantial, especially for those recently bereaved who may be faced with acquiring new skills or learning to cope on their own. A similar learning curve was described by several of our participants who got divorced in later life or whose partner became unable to continue their established contributions due to physical or mental health impairment. Children and friends often help with chores, but there is a delicate balance between assistance and disempowerment as Daniele's aunt illustrates above. Even though she has daughters who visit her every day and grandchildren who regularly call, Lorena in Italy, aged 86, feels very lonely following the dreadful day she woke to find her husband dead in their bed. Covid-19 restricted her activities such as swimming twice a week, but she still manages to cook and clean for herself. Unfortunately, her world restricted further when she was no longer able to travel around on her bicycle, forbidden to ride by her daughters because they are afraid for her health. As a result, Lorena is no longer able to go grocery shopping, a task which is now taken care of by her family.

The work done by family members in providing care is discussed elsewhere in this report (see Chapter 6, Informal Care Worlds). However, it would be remiss in a chapter on work and labour, to neglect to point out the extensive work done by the older adults in our study supporting their children and grandchildren. Often this is financial in the form of pre-mortem inheritance, substantial loans, remittances or assistance with accommodation or the costs of daily living, but equally it may involve childcare duties or support with domestic repairs, chores, or transportation.

Ted, aged 71, a quiet-spoken man living in Northern Ireland provides a good example of this. He lives in a suburban house with his wife who suffers from arthritis and hip pain to such an extent that she can no longer drive. It also keeps her awake at night to the point that they have adapted somewhat different circadian rhythms. Ted's son was a fireman who tragically committed suicide. This devastated the family including Ted's daughter causing her significant mental health issues. As a result, he has been very involved in bringing up his grandchildren, and one of his granddaughters still lives with him and his wife most of the time. As only one of two drivers in his extended family, he spends much of his time driving his wife, daughter and wheelchair bound brother on their various errands, as well as two friends who require help getting to hospital appointments. He is happy to drive them to the shops and hospitals but will wait outside in his car for them to complete their tasks, rigorously cleaning the inside of his car to minimize infection risk and insisting on hands being sanitized as his passengers return.

4.3 Volunteering and Active Participation

Volunteering within family circles was very common among our participants but providing unpaid labour to support external causes or charitable organisations was more variable. Just over one quarter of our participants identified themselves as volunteers, with this practice particularly notable among the older adults we interviewed in Germany and Finland.

Some participants were quite dismissive when asked if they were involved in volunteering. Polly (83) in Northern Ireland felt that it would be too restrictive to her lifestyle to make a regular commitment. She explains: "No it wouldn't appeal. Staying in the same place too long. As well I like variety." Others found a great sense of purpose and usefulness from active involvement in community or charitable endeavours. This was certainly the case with Ted described above, who spends his spare time volunteering in several roles. An active member of his evangelical church community, he has been involved in many initiatives, including donating one night a week of his time to running a telephone 'prayer line'. Prior to retirement he worked for several years as a prison officer and now drives into Belfast once a week to a Charitable Trust set up to support retired staff and their families where he is provided with a list of older adults 'in need' to contact by telephone. Whilst his own family members and friends shop or attend hospital appointments, Ted sits in his car and calls up the people in this weekly list, getting further detail about their problems and needs before making a recommendation of funding or other support actions to the Board of the Trust. On occasion, if deemed necessary by the Board, Ted travels and conducts in-home assessments with older adults requesting assistance.

66-year-old Xenia in Germany argues that with changing demographics around ageing, older adults in good physical or mental health should continue contributing to society. And, she adds, this contribution should be something driven by the older population not given to them, "the elderly must help shape society. We must also demand this, we must not withdraw, we must demand this". Max (70) in Dresden, also strongly advocates voluntary work and works with migrants, older adults' excursions, and a men's club. His wife Laura (69) helps families who have recently had a child, a partly paid role she took on because her own grandchildren live some distance away. Mike (77) who lives in the same city is engaged with the European Network for Older Students and promotes digitalisation and lifelong learning, explains that he became a volunteer because after six months of collecting his pension "the Great Boredom" settled in.

The recurrent theme of older adults helping other older adults can be seen throughout our data. The Global Men's Sheds movement is founded on the premise of older men sharing and using practical skills and experience to help each other and the community. In Germany, a number of participants like Mike or Ludwig were involved in training older adults in digital communications or engaged in groups such as

Activ55+ where volunteers come together to help one another. For example, Susanne (85) who lives in a small town in the Oberbergische Kreis in Germany (see also opening vignette in Chapter 5, Financial Worlds) has recently taken on the role of handling the incoming orders in a volunteer workshop paid for by the city, where several older men provide a free repair service. Taking part in groups like this provides a deliberate two-fold value. It allows her to keep socially active while empowering her children to tend to their own lives:

> "I have to see that I get among people and that I don't involve my children too much either - they all have their families, so I don't want to intrude too much. I have to look for something with my peers."

Walter, aged 80 and living in the same region, is also an active community member. He runs a men's club in his church and has set up a volunteer-based community transport service where until recently he helped drive one of the buses. He decided to step down from this driving role as older adults often require assistance getting onto the bus, either with steps or their wheelchair and he feels he no longer has the physical strength to help with this aspect of the job.

The twin themes of using employment-acquired skills in volunteer roles and the process of stepping down from positions because of illness or physical infirmity were also addressed by Nigel, an 83-year-old man who moved from Jamaica to England in 1959 and then relocated to the county of Antrim in Northern Ireland just after his retirement 17 years ago. He has worked as a stone mason, welder, mental health nurse and a paid caregiver during his various careers before retiring, but notes,

> "I never stopped working, even though [retired], I still do things, I never feel bored, never have time to be bored, because I have so many things to do. I used to go to church as well but because of the lockdown, churches are closed. So, we just do things online and we talk to my friends you see. I used to help my church. I used to be an elder for leading the church and be a treasurer. Things like that and project manage the finance and pay the bills. I dealt with all the money, but because in my jobs I used to have to handle the finances as well as quarterly reports."

Nigel kept involved in this role throughout a series of serious illnesses including a stroke and cancer. Three years ago, at the age of 80 he finally decided he had to give up some of these roles and start "taking it easy" after a bad fall down some winding steps in his town which left him fighting for his life.

As can be seen from the accounts above, there are a variety of reasons why older adults might choose to volunteer. For some it provides a sense of purpose or a way to give back, for others it is a moral obligation, a way of meeting a need of their own, a means of keeping busy, socially engaged, or avoiding boredom. Until the lockdown, Monika (83) in Czechia volunteered on the reception of her nursing home as it offered

her the chance to talk to people and feel she was spending time doing something meaningful. Three participants in Finland, Germany and Italy are involved in running local museums, citing the importance of community memory, heritage, and news. Others are involved in community gardens or sustainability initiatives such as Bernardo (74) in Aveiro whereas Alice (82) in Northern Ireland worked for two days a week in a charity shop prior to the coronavirus pandemic. Under normal conditions, Alice likes to keep busy at least six days a week and the charity shop, along with other activities such as lunch clubs and bus journeys were useful reasons to be outside the house with her husband who was suffering from dementia. Alice says prior to his move to a nursing home, she found it much easier to look after him when he was not in their home. Unfortunately, the charity shop where Alice volunteered is now in the process of closing because it is not making money. She feels this will be a loss of an important social hub in the community.

> "It's all to do with money. When that wee shop was open a lot of people my age and maybe older would come in and have a wee look around, maybe bought something and had a wee talk with you. Those people went out happy they had a bit of company."

4.4 Paid Work in the Later Life-Course

The work biographies of most of our participants are complex and demonstrate a clear tendency towards multiple jobs and careers throughout the life-course. Divorced at 60, Polly chose to turn away from her engineering and sales backgrounds and retrain as a floral arranger and teacher, competing at the Chelsea Flower Show. Likewise, Jakub in Czechia has been working as an accountant for several decades, but at 62 he is feeling burnt out and feels his occupation no longer meets his needs. He has certified as a masseuse and is currently retraining to be a therapist and would like to make a full-time job out of this.

Many of our participants were happy to have left paid work and were (until the pandemic) enjoying expanded opportunities for leisure or putting their energies into care work, family, and voluntary activities. For some of those who did continue work beyond customary or statutory retirement ages, many of the same reasons given for volunteering were also expressed in relation to paid employment such as avoiding boredom, keeping active, busy and connected or feeling useful. Olga (76) in Porto describes how she has worked all her life, from an early age accompanying her single mother who was a maid "in other people's houses". She struggled for many years against her social identity as "the maid's daughter" and eventually went on to work in commerce and build an independent life. After retirement however, she felt she was too young to be stationary and started a new role working as a paid caregiver, until she was diagnosed with cancer. Margaret, also aged 76, living in Northern Ireland argues that work provides a sense of purpose, regardless of the profession or tasks.

> "To me when I was working it give me something to look forward to, get up in the morning, get dressed, go to work. And at the end of the week, you have a wage and you're able to pay your bills or do a bit of saving, to me I really looked forward to work. Until the factory closed down. Then there was no jobs to be got, so anyway my husband had been ill, really ill, so in a way it was a lifeline for me for I had to look after him."

For some of our participants, it was difficult to survive living on a pension and so they chose to continue working longer to make ends meet. Others such as Lucinda (72) in Aveiro rented out rooms in their houses to make extra money. Many continued working for different reasons as we saw in the opening story of Hugo in this chapter who keeps busy with architectural projects of his choosing. Max (70) in Dresden mentioned above for his volunteering work with migrants, is a highly educated gardener and examiner for apprentices. He tried to retire five years ago but his company asked him to return as they could not find someone satisfactory to take over his job. Max still goes to the office twice a week but says that he hopes to shortly stop working fully. This drew a sarcastic comment from his wife, suggesting that it is likely he will keep going. Aside from 'being needed' some of our participants kept working because they enjoyed it. Jiří (69) in Czechia is a self-made businessman who has been running companies all his life. He wakes at 5am every day to go to his factory and work with his employees, He is always on the road and loves the international travel required to create business opportunities. He is certain that the key to staying healthy is staying active. It is only recently that he has started to think about handing over his business to his children, partly driven by the challenges and damage created by the coronavirus pandemic.

Many older adults slowly withdraw from the world of employment or undergo a 'phased' or 'flexible' retirement. Madalena (73) in Aveiro stopped working as a paediatrician in the Portuguese public system at the age of 62 but continued working in her private clinic until the age of 67. Robert (79) in Dresden, on the other hand, stepped down from his work as a translator but continues to work as a freelancer writing articles, poems, and books and has a regular column in a regional newspaper. After his long serving editor of forty years retired, Robert had been worried that his commissions would disappear, but this suddenly changed when a "crackpot" article idea that he pitched to the new editor, was not only accepted but expanded and used for a weekend lead. He worked to a tight deadline, forgetting to eat and exercise but got it finished "And now I'm so high, it's like I've been drinking. That's wonderful." With a new editor receptive to his ideas, he feels that

> "Something is simply going to happen, you can tell. That means my retirement is over, my life as a pensioner is over again. I've already got seven books back on my desk [for writing reviews], or rather on the list. And they want them online."

Beth (93) in Northern Ireland is like Robert and some of our self-employed participants, in that she has no intentions to fully retire but instead made a conscious decision to adjust her working conditions and the type of work she does to better suit her changing needs in later life. Beth is from a small farm background, leaving home at 14 to become an agricultural labourer north of Belfast. The overwhelming theme in Beth's life is one of hard, unrelenting work and rural entrepreneurialism, undertaken with a resigned dedication and few complaints. After a few years, she met her husband, Willie, and with money saved from their time as agricultural laborers, the couple purchased their first farm for £1000. Willie had a reputation for hard work, even in a setting where hard work was mandatory and widely valorised, and Beth at least matched his ethic, even to the point of investing her sparse spare time in raising hens. The farm work was supplemented by wage labour in the local factory, where in a short while, they settled into a routine of her working day shifts and him working nights. As she puts it, "I fed him going out, and he fed me coming home". They invested in land and raising prizewinning livestock, and their increasingly large farms were managed around this punishing schedule. In the 1990s, at an age when many older adults are retiring, they purchased a farmhouse Bed & Breakfast business, with some land attached to transition into the hospitality industry. Now a widow in her 90s, Beth has rented out her land, but still works habitually hard running her B&B. This is out of choice and familiarity rather than need. Giving up is never considered and despite some bouts of ill-health and falls, Beth weighs her 'well-being' in the scales of her ability to labour and maintain her business.

4.5 Conclusions

This chapter has explored three different modes of work and labour carried by the older adults involved in our study. In the first section our participants explain the relationships around taskscapes that construct their domestic environments and how these may adapt to changing conditions and needs over time. This was characterised through the filters of 'couples living together', individuals 'living alone' and those 'living with others than their partner'. Our case studies suggest that gender roles well-established earlier in the life course often continue into retirement, but regularly adjust quickly in response to emerging needs caused by accidents, illness or deteriorating physical or mental capabilities. The theme of learning new skills is also explored in this context as well as life course transitions such as bereavements or divorce. This section concludes by pointing to the diverse contributions of older adults to the support of their adult children and grandchildren.

The theme of unpaid work beyond the household and family was examined through the lens of volunteering. Approximately one quarter of our participants identified themselves as volunteers, with our case studies suggesting a diverse range of reasons given for participation. These include keeping busy and social connected, avoiding boredom, moral obligation, a sense of purpose, a way to 'give back', retaining or promoting community cohesion, memory, and communication, encouraging

sustainability, and older adults helping other older adults. Younger participants pointed to the 'Great Boredom' experienced some months after retirement or the fact that they were baby boomers or the "Rolling Stones generation" that must not withdraw from society but demand to shape it.

The final section of this chapter develops insights about paid work from the perspectives of those who choose or are forced to take employment or run a business late into retirement. Beyond the obvious financial advantages, many of the reasons given for continuing with paid work reflect explanations for engaging in voluntary work such as a desire to be useful, keeping busy and socially engaged. Others were encouraged to stay in work by their companies or were slowly 'phasing' into retirement by reducing hours, accepting commissions and 'gigs' or adapting work conditions and duties to roles more accessible to their changing bodies and family circumstances.

To conclude, we return to the opening case study in this chapter. When asked about getting old, Hugo in Portugal replied, "What I know is that we, as a community, are not used to or prepared enough to help older people to be useful in our society. This would be a way to improve their self-esteem and to care for those who have no conditions. I think that ageing population is a new and serious issue for our country to deal with."

4.5.1 Insights and Reflections

Considerations for policymakers, solution developers, and service providers:

- How might retirement be reframed from being the end of a person's working life to the beginning of a different work-life balance? This chapter showed work and participation in the labour comes in many forms (paid work, volunteer work and household chores). Official retirement should therefore be understood less as a sharp cut-off point and more as a transition to a different relationship to work.

- While many older adults need assistance or care to remain in their homes, they equally want to remain in control of their lives and pursue their personal interests and preferences while maintaining their dignity. How might the delicate balance between assistance and disempowerment be managed? In what way could existing and new services be used to create work that is socially engaging and purposeful?

- Structural problems like lack of money should not be transformed into therapeutic problems What underlying knowledge gaps (e.g., handling finances, cooking food, digital skills) could impact the efficacy of products, services, and policy changes?

FINANCIAL WORLDS – SPENDING & AFFORDING
Chapter 5

Chapter keywords: Gender, Pensions, Home Ownership, Rent, Budget Management, Heating, Power of Attorney, Sandwich Generation, Affordability, Decision Making

5 FINANCIAL WORLDS – SPENDING & AFFORDING

Susanne

Susanne is an 85-year-old recent widow living from Radevormwald, a small town in West Germany. If you were to meet her in person you'd be charmed by her courteous, friendly yet independent demeanour. Radevormwald is a municipality of the Oberbergische Kreis region, a naturally splendid valley region, home to a blend of towering green forests, lush sweeping farmland and surrounded by pockets of deep man-made lakes. The regional town is situated adjacent to the River Rhine in the West of Germany. At the time of her interview, Susanne was slowly recovering from a recent fall she had when she was rushing to water the flowers in front of the house. She tripped on the front step of her home because, as she said, "I probably didn't lift my foot high enough". This fall resulted in a fractured wrist and follows an existing accumulation of physical injuries and ailments from the past.

Susanne claims to not be active with hobbies and prefers to maintain a consistent daily rhythm, where she enjoys the rituals and habits of everyday life. Furthermore, she likes to read a lot and enjoys watching TV, which in her opinion has a lot to offer as well. During the summer she perches on "a nice seat outside… with nice garden furniture" and enjoys reviewing her garden meadow with beds all around and a big magnolia tree, or she may go to the bird feeder to bountifully restock it with seeds. In Autumn, she adjusts to the seasonal changes and makes use of her nice sunny balcony, a well-placed location of the house to sunbathe during a brief window between two and three in the afternoon.

For the last fifteen years, Susanne has also been involved as a volunteer in *Aktiv55+*, a regional support group for older adults that offers activities and runs a locally established 'repair service' in which Susanne works twice a week handling the incoming orders and general operations for people from the surrounding.

> "This is from the World Health Organization… So, I've been there 15 years since this started. I joined the group right in the beginnings."

Susanne's children have moved out a long time ago and are settled elsewhere but she still receives direct support from her daughter, who helps her with the grocery shopping once a week, on Thursday after work. Given that Susanne, as she puts it, is "not that good on foot anymore" she requires the use of a rollator and her car to get out and about. Her mobility issues are often exacerbated by the hilly environment.

> "So, we belong to the city, but it's a quarter of an hour to walk. And it's uphill - if I go out the front door, I have to go uphill straight away. (…) And that's bad

with the rollator and it takes too long for me and it's also too difficult. And that's why, thank God, I can still drive the car, so it still works. And in the city, where it is then, I can go from shop to shop with the rollator, for example to the pharmacy and the doctor and whatever I have to do. I can do that. And besides, my daughter drives with me once a week. So that's how we split it up."

Susanne also receives support from the *Diakonie*, a social welfare organisation of Germany's Protestant churches offering a wide range of care support, including practical aid and legal representation. With costs for these services covered by her long-term care insurance (a section of the public health insurance in Germany), the group had originally helped Susanne take care of her sick husband, but the care service has now extended to Susanne. This was decided in conjunction with her family doctor who helped organise the services, as Susanne believes, "because I had taken the medication incorrectly". She is grateful that the group helps her keep track of and regulate the dizzying array of medications she takes. The group also provide essential non-medical supports like general housekeeping and maintenance.

> "So the economic department, they also help me. They come to me every 14 days for two hours and help me make my bed and they wipe the floors and clean the windows, which is difficult. I take advantage of this help and I am happy about it."

In her earlier years, Susanne had to stop working to raise her children, as was customary for the time. She recollects that she had no one to look after her children and thus was unable to participate in the workforce for about five years, "so of course my pension is not high." Because of her limited and often part-time periods of work she only has a small pension and is still dependent on the widow's pension, which is about 60% of her deceased husband's pension. However, Susanne considers herself one of the lucky ones, comparing herself to other widows that may not have worked at all.

> "They just lived on the husband's income and they're even worse off. They only have their widow's pension now and they also have to cut short".

Regardless of the additional income she currently has at her disposal, the reality is that Susanne must be cognisant of her spending and even basic living costs such as covering expenses like electricity, heating and water are high and pose a challenge.

> "I still live in the house and have to heat it - somehow more costs are incurred for such a house. Electricity and heating, water, everything you need, and having the garden looked after, I can no longer do that alone. Of course, that also means a lot of money".

To afford the costs and remain in her home, the family house has been assigned to her children so that they can help her cover house fees, insurance payments and other

regular costs. Instead of downsizing, she would much rather stay in her home until the end of her life. With that in mind, Susanne readdresses the humbling practicalities of her day-to-day living expenses in old age,

> "I don't have to buy anything anymore. I just have to take care of myself. But the oil heating, of course, for the whole house, I have to see that too. But somehow we'll get it."

Susanne depends on a multitude of services she cannot do without and needs to attend to her in-person medical check-ups or drive the car to town where she can use the rollator. These processes all require her attention. However, these tasks and decisions, whether medical or financial, are often made while psychologically alone. Since the death of her husband, she has been living in her house alone, and it's something she still hasn't "gotten the hang of dealing with" just yet. As a testament to her long periods of isolation, she often excuses herself as she loses her voice during the interviews, all aspects of modern life are entangled with financial requirements. We learn about the daily expenses she has to upkeep, the support she requires and the costs she endures to maintain her autonomy. This chapter develops these insights and explores key themes such as gender and pension challenges, financially dependent family members, homeownership issues and budget constraints. This section concludes with some final thoughts and summarised insights. While reading through this chapter, it is important to keep in mind that financial health can play a role in individual health outcomes (Weida et. al, 2020)

5.1 Gender Pension Issues & Non-Standard Employment

Pension inequalities for our female research participants emerged as a salient theme across many of our case studies. As Susanne explained, she considers herself to be one of the fortunate ones when it comes to her pension. In this section we'll look at the contexts in which these inequalities emerge and provide further insight into how relying solely on a partner's pension can be detrimental for a person's financial wellbeing.

An example of how roles in the household can impact an individual's financial wellbeing can be found in Northern Ireland. Margaret, a 76-year-old family caregiver, had spent the majority of her adult life (the last forty years) as a primary caregiver to her husband with a significant physical disability. She also managed to raise two children during this time as well. Margaret notes the most challenging aspects of her husband's disability meant she had "to be there at his call all the time". Due to her husband's poor medical health, she was required to assume the role of sole breadwinner for her household, working "shifts in order to help pay the bills and all". In essence, she was practically alone in both financially and structurally maintaining her family.

Thankfully, there is a strong social welfare state in Northern Ireland, so Margaret has not aged into absolute financial destitution. She has a home to live in and her husband receives medical treatment. But this case reflects a snapshot insight into the broader scope of existing research on the topic of non-standard working and marital biographies and their consequences on old age income (Möhring, 2021).

Another participant in the German Oberbergische Kreis region succinctly described how the support of a widow's pension may not be a sufficient guarantee of financial security. Evelin, an 80-year-old widow who had worked hard all her life, highlighted that "your pension will be less to a large extent… [but] I would say, the electricity and the heating and also the rent remains the same, whether you then live alone in the apartment or whether you then live as a couple, that has not changed the expenses". Evelin explains that even a humble and modest lifestyle, requiring only essential services, still must operate around the material realities of income and expenditures.

The point of this section is not just to highlight the challenges of meeting expenses in old age, but how many women, specifically widows like Margaret from Northern Ireland and Evelin from Germany are at increased risk of losing their self-sufficiency and autonomy. Losing this autonomy could not only make them more dependent on family members but also the systems of social welfare and societies in which they live.

5.2 Financial Dependencies

In several of our cases, we spotted the topic of significant downward intergenerational support, of both a practical and financial nature. In some cases, we see this when an adult child has a physical or cognitive disability or significant medical condition, in others, we see issues of addiction as well as the reverberations of downward economic cycles, such as loss of employment when a local factory permanently closes. This idea supports existing research into the 'sandwich generation' and the roles they assume in family units assisting both very old parents and their own adult children (Miller 1981, McGarrigle & Kenny 2013). Although considerations regarding a state's social policies (Deindl and Brandt 2011), should be factored in when estimating the likelihood of these downward intergenerational financial transfers happening.

In Finland, Bertil, a 78-year-old man living in a rural area in the South has had various professions as before his retirement he worked as an entrepreneur. Bertil has been married two times in his life. One of his stepsons' co-habits with them from time to time. This stepson suffers from an "alcohol problem". Bertil isn't happy about this. "Fifty-one! He's an adult man living with his parents now. That's what causes friction between me and my wife… it stresses me out, because my blood pressure is elevated. Even though I have the medication for it, it keeps fluctuating". Beyond the medical impact of supporting his stepson, Bertil also alludes to the potential financial costs, even with both he and his wife having a "fairly good pension". Having an extra member

in the house is putting a strain on their budget, "meals and car service expenses and insurances have become a bit of a burden. We've even had to take an additional loan, so I do not feel good about that".

In Porto, Rosa, a 75-year-old widow and mother of two daughters has worked all of her life as a public employee and has always lived on a minimum salary but still manages to support her descendants financially and otherwise. Since the closure of the local factory, one of her daughters is unemployed as both her daughter and son-in-law "got laid off". Since then, Rosa allows their young family to live in her house while she moved into the adjoining annex and even pays for their groceries, "She'd go with me, she'd take whatever she wanted, and I'd pay for it". Furthermore, Rosa takes care of her grandson who lives alone since his mother died from cancer. This grandson is financially dependent on Rosa who also cooks for him daily. "He is a boy who can't live without me, he doesn't know how to do anything without me". But while Rosa enjoys helping her family as best she can, the grandson suffers from schizophrenia and has had violent outbursts in the past when not on medication. Rosa's guiding principles on continuing support for her family is based on a moral stance to care for her family, even though she recognises the toil of this existence.

The key insight from Bertil's and Rosa's experiences, is the need to interrogate any assumptions related to support only moving upwards between generations. When evaluating an older adult's ability to afford new solutions or potential changes in income, to what extent could other dependencies in their lives be affected by those changes?

An interesting observation for other researchers is to consider how similar financial transactions, addressed above, may be hard to find in aggregated quantitative data. Intergenerational financial transfers like these could be hidden from view by their categorisation, e.g., under an increased food expenditure, bigger gasoline purchases or extra 'gifts' spent on grandchildren.

5.3 Material Security and Home Ownership

The topic of material security in the form of homeownership and how its access has an impact on the life course, emerged from our data. Most of our participants were dismissive of the idea of moving to a nursing home and looked to stay at home for as long as possible (see also Chapter 7, Formal Care Worlds). In Susanne's case outlined above, she would rather stay at home "until [her] end comes". Given the consistent expectation to remain at home for as long as possible, this section will look at the financial aspects of homeownership. This will be done by reviewing two interesting concepts through the experiences of two different research participants; Hannelore's challenges of renting when retired and Alison's experience with trying to financially utilise her home when she doesn't have power of attorney. These cases

serve as a way of looking at how homeownership plays a factor in the financial aspects of later life care.

In Dresden, Germany, we spoke with Hannelore, a 76-year-old woman living alone in rented accommodation on the outskirts of Dresden. She used to work as a teacher during the time of the GDR, had divorced from her husband and was left as a single mother. Hannelore never remarried. During her interviews she talked about the challenges of finding affordable rents while living on a pension,

> "Yes, and then the flat I had was still very, very expensive at the beginning. But then the rents were lowered a bit and when I went into semi-retirement and earned less money, I tried to get the rent lowered, but I didn't succeed."

As she grows older and less able to perform certain physical routines, she worries about her ability to remain in her current home. As she is not the owner of her apartment, Hannelore is dependent on her landlord to make changes that could facilitate her living longer independently but feels that it is not possible to make alterations to the flat:

> "It's not my flat, I've only rented it. And I can't imagine that my landlords would rebuild it, I don't think so. So, if I can't manage it anymore, I'll probably have to think about where I'll go. Even if I can't manage the stairs anymore."

In Northern Ireland, we see an inability to access the potential financial benefits of homeownership in later life. Alison is 82 years old. For ten years she cared for her husband with Alzheimer's. She has been living alone for the past three years since her husband was accepted into a nursing home. Alison has experienced frequent, and significant, financial hurdles as she doesn't have "power of attorney" over her husband. This has caused her numerous issues like trying to cancel a car insurance policy because "they have to speak to [her husband]" as well as attempting to gain access to her husband's private pension. Alison says her husband "has a wee private pension, and I can't touch it, because it only has his name on it". Alison finds it disturbing to have to see people like herself, "people who have worked hard all their lives … losing their home to pay for their welfare". However, her current issue is punctuated by her inability to sell her home, "Because it's in my husband's name, I can't sell it because he can't sign for it … the same as … the [nursing] home can't get any money out of it because my husband is not able to sign". Beyond the emotionally displeasing aspect of letting go of her home, the inability to financially utilise that home is a deeply frustrating affair for Alison.

As people in similar situations to Hannelore and Alison move through different stages of the life course, considerations could be made as to how people can participate in shaping their living conditions and what processes are in place to facilitate these life course transitions. In Hannelore's situation, homeownership and financial limitations

could put her at risk of becoming more dependent on family members and the state. In Alison's case, legally not owning her house is putting her under financial pressure.

5.4 Budget Management and Restrictions

An essential aspect of the financial world is to address the material realities of later life through the lens of incomes and expenditures. This section will highlight some of the routine expenses many participants must pay. It is useful to look at this aspect of the later life course because it helps provide insight into the context in which decisions are made, what choices people think they have available to them and how access to money impacts the later life experience.

Danae is 69-year-old widow living in a village in central Greece. She is retired from her role as restaurateur and cook. Through one of her responses, we learn about the similar impact of having a widow's pension that our vignette of Susanne had addressed earlier. "When I had the shop with my husband, it was very different. Since my husband passed away, I was left with a pension of 580 euros. It is very difficult. I need 100 euros for my medication. I also need to pay the electricity bill, the water bill and the mobile phone bill". We see that her need to cut back and operate on a lower budget has caused her to forego certain household utilities. "I do not have a landline anymore. I couldn't afford it. I can make it through very difficult, but that's fine". Danae also goes without other essential items. "I can't offer the essential support and healthcare provision for myself, due to my financial status. Now that I have to buy diapers, I consider it a lot. If I need to buy something extra, for instance a different pill or an ointment, I won't do it, because I can't afford it". Avoiding making certain purchases like these could end up increasing her health issues, thus costing her more in the long run.

In Czechia, we find Natalia, a 78-year-old retired teacher. She lives alone in her flat in the city centre since the death of her husband. She faces the same issues as Danae as well as many other participants, even with the financial backing of her son. "He bought the apartment [for me]". Her budget limitations are most prevalent when speaking about medication costs.

> "I don't take many of them, but I give a lot of money for the drugs and now I believe in the herbs and the stuff, the supportive ones, and it's so terribly expensive that I can afford it only once in a while, I can't buy it all the time."

Natalia, in response to high medication costs, will prioritise using off-brand or "replacement" prescription medication so she doesn't "have to pay extra". But her pension budget limitations will also mean that she puts off doing pleasant things.

> "You want to buy a book, you want to go to the theatre, you want to go there, and it's not enough. Take the cost of a ticket to the theatre. That's at most once

a quarter or at most once a month, but it's such a strain that you can't afford any other things, like buying toys for your grandson".

Budget limitations, like these, affect both the medical and mental well-being of an individual. Instead of gracefully ageing in place, we see Natalia and others making choices like, what's now possible with less. This is quite reminiscent of Susanne's perspective as she notes, "it's all a give and take, and you have to think about what [help] you can afford".

The point of highlighting these issues is to remind service designers and solution developers to consider the viability of offerings. Is this something an individual can reasonably afford, if not, what will they have to go without to access their product or service? What existing infrastructure needs to be available for a solution to be used?

5.5 Conclusions

Taking note of the observations made in this research, we are left with insights about what new questions to ask as we develop services and technologies for older adults. We learnt about the financial hardships of widows living on a percentage of their husbands' pensions and how this practice, puts many women at an increased risk of losing self-sufficiency. We gain a greater context into the requirements of downward as well as upward intergenerational financial support and the challenges of daily expenses in old age.

The goal of highlighting these insights is to unearth potential assumptions that developers and policymakers might make when exploring solutions to complex human problems. The people we are trying to serve are all continually making choices in varying dynamic contexts. It is best to go and investigate those contexts to ensure a problem is actually a problem, and if it is being solved.

5.5.1 Insights and Reflections

Considerations for policymakers, solution developers, and service providers:

- This chapter highlights the challenges of meeting expenses in old age and especially how some widows may have less autonomy by being reliant on their husband's pensions. In what ways could systems recognise non-financial societal contributions done by women during their life to reduce the odds of impoverishment and subsequent loss of self-sufficiency?

- In this chapter we demonstrate that successful participation with technological innovations is not only dependent on the usability of the tool but crucially also on the availability of essential infrastructures, such as internet connections, and the means to afford them. What foundational materials/ access to existing

systems are required for a solution to work? How can older adults gain meaningful access needed for solutions?

- Given that we have observed and reported stories about getting by on a budget, are there opportunities to reduce the cost burden of solutions for customers and users while still developing a financially feasible and effective concept, product or service?

- Financial support in the later life course can involve bidirectional resource transfers in and between generational cohorts. Assessing older adults' economic and sociocultural contexts while developing solutions should be done to counter unhelpful assumptions and biases about target demographics.

INFORMAL CARE WORLDS – PROVIDING CARE
Chapter 6

Chapter keywords: Dementia, Caregiving, Care work, Community Care, Respite Care, Peer Support, Gender, Independence and Interdependence

6 INFORMAL CARE WORLDS – PROVIDING CARE

Eleftheria

Eleftheria (75) and her husband Thanos (85) live in a house near Larissa, Greece. They have two daughters and five grandchildren. Eleftheria has finished elementary school and, at the age of 13, started working in her father's tailor shop. At 19, she married the taxi driver Thanos from matchmaking typical in Greece at the time. While she had not chosen him, over time, Eleftheria's love for Thanos grew seeing his pleasant, cheerful, and generous character. "I was lucky. Thanos is a wonderful person, my sister who got married out of love did not have a good life like me." Together they enjoyed travelling and even moved to Switzerland for six years. When they started a family and returned to Greece, they had a peaceful and happy life, humble but filled with joy and many friends.

In the past ten years, their life changed as Thanos suffers from several serious health problems. He has been diagnosed with diabetes, hypertension, COPD, and dementia. Especially the latter poses a challenge to the couple's sense of freedom and independence. Describing an "embarrassing situation", Eleftheria explains:

> "One day Thanos went to play cards with his friends. Returning home, he lost his way. A neighbour found him and brought him home. He was sweaty!"

Afraid of losing his way again, Thanos stopped leaving the house and, for the last three years, did not even go out to the yard of their home. Nowadays, due to his worsening condition, he can barely get out of bed and moments of clarity are rare to none. Eleftheria is the one to exclusively undertake all the care and support for Thanos. She provides him assistance with tasks bathing, feeding, and dressing, or his daily personal hygiene needs. She is also responsible for doing the housework, shopping, visiting the doctor for his prescriptions, going to the pharmacy, completing the paperwork, and managing the finances. In addition, she is responsible for the proper administration of his treatment and to provide companionship and emotional support to her partner.

Being her husband's full-time carer, Eleftheria is always worried about his safety and closely monitors his activities to ensure his wellbeing.

> "One time, I left him alone for a while to go shopping. When I returned, I found him under the bed. It was impossible to pick him up, so I had to call a neighbour to help me. After that, I put a railing on his bed."

Thanos' dependence has made it increasingly difficult for Eleftheria to leave the house or to enjoy social contacts. In the past, both Thanos and herself liked to have fun and went to the taverns regularly. Today the restrictions imposed by his illness determine the everyday life she leads, and Eleftheria feels uneasy leaving her partner unattended. When her daughter asks her to join the family to the taverna, she regularly refuses, prioritising her husband's needs over her own:

> "I keep telling my girls every now and then not to feel sad for me. I enjoyed everything, I have so many experiences. Everything is fine, I will be here with your dad as long as I can."

Thus, despite her daughter's attempts to encourage outdoor activities, Eleftheria's response remains the same: "I always say 'No I am not leaving him. You can go, I have eaten and had fun."

Accepting of the moment, Eleftheria's take on life goes beyond the present restrictions. Drawing on shared memories, she gathers strength that helps her through the challenges of the present. However, thinking about the future, Eleftheria is concerned about the state of her own health. What worries her most is that if something happened to her, Thanos would be left alone with no one to look after him: "Our children have their own lives, their own problems." Nevertheless, while these and other issues pose obstacles to caring for herself properly, she does not complain. At the end of the day, when Eleftheria has finished all her duties, she sits in her favourite armchair and flips through the album with photos from the past, stating:

> "I had a happy life with my husband. Do not worry about me, I have lived my life. I have no complaints, now I just want to take care of my partner."

Eleftheria's devotion to her husband is known in the neighbourhood, prompting them to call her a hero, to which she modestly replies, "I just smile and reply that I am an Ordinary Woman."

6.1 Introduction

This chapter traces the role of older adults as caregivers and the purpose of *informal care* in lifeworlds, the processes through which it is delivered, and how people participate in such practices. Eleftheria's story presents the needs and challenges of informal caregivers vividly. Insight into her bodily and emotional commitment also demonstrates how technologies for remote monitoring, training in in-home care provision, a larger care network and institutional care services could support her in meaningful ways. Her case study also suggests how greater availability of information about the progression and symptoms of her husband's chronic disease, appropriate treatment advice, online doctor's consultations, and in-home visits covered by public

health insurance would help Eleftheria and other caregivers cope better with handling the daily routines and thus improve her own wellbeing.

Care practices among intimates in private settings are often lumped under the umbrella term "informal care" and generally placed outside the boundaries of "formal" care systems of services delivered by professional and paraprofessional healthcare providers (HCPs). Triantafillou et al. (2010) suggest that *informal care*, also often referred to as *family care* or *unpaid care work*, is defined as care provided to older and dependent persons by a person with whom they have a social relationship. All three terms, however, carry connotations that are not always applicable for the phenomenon in place as caregiving often happens between friends and neighbours and the "unpaid" facet as a definition for care practices between intimates is complicated by tax incentives, care support payments and "care for cash policies" available nowadays in most welfare states (Lundsgaard 2005). Moving beyond such narrow and often inadequate definitions (see for example Zigante 2018), we are defining informal care practices as those focussed on maintaining or restoring the wellbeing of intimates by other intimates such as family, friends, and neighbours. This approach helps understand care as "a resource and relational practice" (see Buch 2015) that impacts not only the lifeworld of the recipient but also of the caregiver and their support networks.

In our research, two-thirds of our participants have shared their experiences of current or recent caregiving and told us about the effects, challenges, joys, and sorrows that come with the role. This comes as no surprise, as 'informal care' forms a significant part of the total long-term care provision in European countries, with estimates of care delivered in this fashion running as high as 80% (Hoffmann & Rodrigues 2010). Depending on the country and how informal care is defined and measured, this means that the total number of carers constitute between 10% up to 25% of the entire population of Europe. The frequency by which seniors become critical agents in care structures needs to be recognised as the future of integrated care systems largely depends on untrained family members and friends who enable the continuation of independent living of more frail and dependent older adults. As our data show, much of what is defined as 'formal care' in the home is contracted, or at least mediated, by intimates seeking care for more dependent relatives. Proper understanding of informal caregivers' real-life scenarios, therefore, will allow institutions, policymakers, and communities to provide caregivers with the support they need to uphold their contributions.

With that in mind, this chapter explores the complex universe of informal caregiving practices by older adults ranging from physical through emotional solidarity to financial support and managing care structures to full-time caregiving. We first examine care of the self and others, possibilities of technological support and gendered expectations of care giving in home care settings. We then look at community-based care, peer to peer support and the use of social (media) networks and tackle the issues of respite

care and financial support. In the third part we address generational dimensions of care in family networks in which older adults are caregivers to the younger generations and engage with the question of new beginnings once the needs for care have shifted. In the conclusion we summarise core insights and highlight the ways in SHAPES can contribute to facilitating care needs with its technological and digital solutions.

6.2 Care, the Self, and Technologies

Care is a cornerstone of people's lifeworlds and a central part of any holistic approach to the concept of wellbeing. Caring for the self includes physical activities, a healthy diet, following medical advice for the management of chronic conditions, exercising, social inclusion, homes suitable to the needs of ageing persons, a sense of purpose, safe surroundings, and mobility to allow independence (see Chapters 1 and 2 for further details). 'Informal' caregivers are often thrown into their roles unexpectedly and need adequate support to lower the negative impacts on their health and wellbeing as the new role can place great pressure upon them and their social networks. The new circumstances can lead to social exclusion, reduced (volunteer and paid) work, leisure activities and holidays. Additional costs from medicines to care technologies and services can challenge limited resources and, in some cases, put the caregiver at risk of poverty (UNECE 2019). Furthermore, most informal care givers are untrained in care practices, and the new role introduces a process of change, adaptations and learning that involves physical skills and emotional efforts far beyond practices people knew at the outset. Transforming the home to meet the needs of care is an essential part of the process. Commonly, stairlifts need to be built, bathrooms or doors adapted and 'traps' such as unstable furniture or slippery rugs removed (see Chapter 3, Moving through the World, for further details). While landlords' regulations often restrict some changes in rented apartments, even in privately owned homes, financial aid is needed to enable essential spatial changes. Insights from many of our participants suggest that it is important to seek ways to empower older adult caregivers to enable caring for the self while caring for others.

With 13 years of experience caring for her parents, 70-year-old Jutta knows the ins and outs of assistive technologies. While she frequently used her own body to help her ageing parents get in or out of chairs, to help them up after a fall, or to assist with basic hygiene needs, technologies helped them retain some independence: "There are these raised toilet seats, for example. As a result, my mother was more independent again and was able to go to the toilet on her own. It has really helped a lot and has also preserved her dignity in this regard." It is easy to forget, in an age of the promise of digital wonders, how important such analogue/legacy technology is in the lives of many older people, allowing the preservation of dignity and maintaining 'regular' life at home.

Caregiving within families involves emotional labour as nursing practices such as washing a loved one or feeding them changes the level of intimacy and puts into

question established roles in relationships. Both parties face the challenge to overcome prejudice and perceived boundaries of intimacy. Reflecting on the changed relationship and overcoming shame, Jutta says, "I think it was difficult for my father. He comes from a generation where you never really showed yourself undressed to the children." To Jutta, the physical aspects of caring was never an issue, and she highlights that caring for the parents also facilitated positive experiences.

> "I have seen that death and dying is nothing to be scared about and that in the best case, you just slide away. For me it was precious that I could experience it so directly. But I've also learned that aging is not for cowards, it's a very difficult thing. Well, it affects me now myself."

Jutta's biggest challenge was the need for constant and instantaneous availability to her parents which also impacted her relationships with friends, grandchildren, and her husband, who divorced her soon after she took on the caregiver's position. On constant alert and having to accompany her parents on all errands made it difficult to act spontaneous, follow freely her own rhythm or rest in the evenings. However, when they decided to buy a wristband with an alarm button directly linked to an emergency alert service, which her mother always wore, she finally found some relief and peace, sleeping through the night again.

Supporting people in need of care is challenging and cognitive decline enhances all these problems as care recipients loose organisation skills, start wandering during the night, or no longer remember to take their medicines, et, drink or use the toilette. For years, Leonor (66) from Porto cared for her husband in their shared home and witnessed his progressively worsening dementia. Despite her caring deeply, she emphasises that the pressures of their shared living arrangement made her act in ways she later regretted.

> "I was so tired! He would do anything, and I would get angry (…) and one day here he gets me all dirty, he poops and dirties all the walls and I, or I don't even know how to explain the nonsense that he is capable of, and I find myself taking my arm and wanting to hit him. I say this many times in Alzheimer's meetings because people are ashamed to think they are human and lose patience and I reached a point where I lost patience, I just felt like hitting him, I was exhausted. I'm not one to make depressions, otherwise, I would have had one for a long time, but my way of reacting was to externalise, and I wanted to hit, until I squeezed his arm. Then I stayed in myself and said, 'my God Afonso, I'm sorry, we never reached this in our lives, never', but he didn't even react anymore. I felt even more guilty until I said 'no, it's time, I don't want this to happen anymore in my life, because this is what happens to the sick person'. So I went straight away to see if there was a vacancy at the nursing home."

While Leonor is breaking an assumed taboo in sharing this story of violence with us, other research participants experienced similar frustrations and shared feelings of impotency and helplessness when losing control, even in her own home. Support groups, open and honest exchange with others in similar situations, respite care leave, and improved availability of community care can offer much needed assistance. In Leonor's case, moving her husband to a care facility was a solution to increasingly challenging and untenable living and caring circumstances and improved their relationship.

Most people who become caregivers cannot choose to take on or refuse the role. In these circumstances, technologies and professional care services can help the carer choose the breadth of time and emotional labour they invest in caregiving. Stairlift chairs, alarm pendants and wristwatches, toilet and shower aids are devices that regularly assist older adult caregivers. Additionally, those who do not have the bodily strength to help patients with dressing and washing can employ service providers to come by daily to help with these tasks. Once all these avenues are exhausted, and the care relationship becomes too draining, nursing homes may be considered as an alternative solution. After 13 years, Jutta and her mother decided that it was no longer possible to continue with homecare and that it would be better for her to move to a dedicated care institution. This move brought freedom to Jutta to finally enjoy her pension and explore what she will do with her time. Moving to care facilities is, however, an idea rejected by many families and often associated with "social death signalled by institutionalisation" (Angus et al. 2005, Gubrium & Sankar 1990). Often cultural traditions expect potential informal caregivers to 'return the favour', fulfil their duty as a child, and maintain face in the community.

6.2.1 The Gender of Care

Every fifth person over 80 and one in 20 over the age of 65 suffer from a form of dementia (McHugh et al. 2012). Caring for a person with dementia requires heightened alert of the caregiver as disorientation and confusion are known effects of the disease. Eleftheria's case already demonstrated the issue when her husband got lost while walking home. Since then, she has been apprehensive about leaving him alone unattended. In consequence, as his dementia progresses, her worries for her husband effectively bind her to the house, reduce her social contacts drastically and endanger her due to lack of physical exercise and emotional exhaustion.

82-year-old Alison from Northern Ireland experienced something similar. Before her husband, who also suffers from dementia, went into the care home three years ago, she had been his caregiver for ten years. During all that time, she had to take him with her everywhere, to the charity shop, lunch clubs, Alzheimer's clubs or just on a bus journey. She found it easier to look after him when out than leaving him in the house where he could wander off if she were not there. Furthermore, she adapted the home and had labels on all the cupboards so he would know where things were. Most

importantly, she had to keep the doors locked and hide the keys so he would not wander off. Alison and her husband have two sons and a daughter who visit them regularly. However, during the coronavirus pandemic lockdown, no one could visit her husband in the nursing home, which resulted in a lack of stimulation that the family believes caused a significant deterioration in his health. He even went into palliative care which allowed visitations, and luckily now his health improved. Alison keeps very busy in normal times, goes out six days per week, and even works in a charity shop twice a week. Her independence is crucial to her even more now since her husband has gone into the nursing home. What she worries most about are financial issues caused by the inability to get power of attorney as bank accounts, the house, and pensions are all in her husband's name, and she cannot access them. Such dependency highlights prevailing gender inequalities in which women are often disadvantaged. The responsibility of care relies disproportionally on their shoulders, be it nursing care or childcaring activities. They, therefore, often have either a lower income or none at all, compared to their spouses. Such dependency is also reflected in the potential danger of age-related poverty, specifically after their partners' pass away (for more on finances and gender see Chapter 5, Financial Worlds).

The implicit gender dimension of caregiving highlights traditional culturally and socially ascribed expectations of women. 83-year-old Cecilia from Finland, whose husband lives with Alzheimer's, explains the hardship of caring for her partner and the difficult balancing act of the two roles.

> "After all, I would like to remain a wife. But without even noticing it, I started taking on the caregiver's role before I was officially a carer. So, I'm in-between those two roles – right now, I'm more in a caregiver's role. But of course, I'm his wife 'til death do us part'."

Feminist scholars like Engels (1978) argue that care is a form of social reproduction that involves reproducing and sustaining both biological and social life over time and across generations. Persistently undervalued in capitalist economies, the unequal distribution of reproductive labour by gender, race, nationality, and class intensifies social inequalities (Colen 1995, Glenn 1992) and particularly shapes the later end of life (Buch 2015). The new demands imposed by caregiving transform established relationships and have an impact on the self-identification of carers. While Cecilia's quote demonstrated her struggle with the situation, Eleftheria represents a position of acceptance. While taking care of her husband is often overwhelming, she emphasises the love she still feels for him and that the memories of past joys, of a life they had together, give her the strength to devote herself to this task now and to remain content in her role as his wife.

On the other hand, Leonor from Porto, who openly speaks about taboos in dementia care (see details in previous section), opposes the assumed normality of the caring woman, wife and mother who will dedicate her own life to the needs of her husband.

Like Eleftheria, for years, she looked after her husband in their shared home. Even now, since he had moved to the nursing home for professional care, she calls him every day and, before the Covid-19 pandemic, visited him regularly.

At the same time, since he is gone, she feels more alone now. Memories of a once beautiful marriage are not enough for the agile ageing woman, nor were marital promises such as "in sickness and in health" or "till death do us part". In a way "My partner is already dead," she says, "He died years ago. And since a lot of time has passed, I just wish to fall in love again."

6.3 Community Care

Community care describes long-term professional care for older persons provided within the community or neighbourhood rather than in hospitals or institutions. Such concepts of ageing in place commonly involve informal as well as professional support for people living in their own homes rather than services provided in residential facilities. As a practice and process, such community-based systems transfer responsibility from individuals to social groups and from state institutions to local welfare agencies thereby creating networks vital to functional assemblages in which older adults can remain in their homes. Community care services offer support in all aspects of life, including social and physical activities, personal care, mobility, and meals provision, amongst other things. Health care policies have equally increased support for paid or hybrid shared cost homecare programs with various technologies that transform experiences of both home and care (Lopez et al. 2010, Pols 2010, Willems 2010).

Integrated care provision enables semi-dependent older adults to remain in their homes despite their health or age-related needs. Service providers come to their homes to provide domiciliary or personal care, manage medication, or organise transport for patients to attend doctor's appointments and social events. Community care includes social inclusion services. Furthermore, to enable participation in community activities, digital social platforms support seniors' independence, sustain personhood, and bring relief for the informal caregiver (primarily relatives) through better integration of the individuals in society and reduction of isolation and loneliness.

Often, active and healthy older adults are involved in providing these services as volunteers (see Chapter 4, Working Worlds) or help as informal caregivers to navigate and handle complex care systems. Where and how to apply for financial support? What home care options exist? What about support on the weekends? Are there digital and technological tools that help manage needs? What local and national support groups provide help? To build these networks of care, older adults with intense care needs often rely on informal caregivers to manage and put in place these services for them. In these contexts, it is often the task of the carer to research support institutions,

identify financial aid to pay for services, retain regular contact with the service provider, and monitor changing needs, arguing the case for adaptive or additional resources.

Charlotte knows care – professionally, personally and as an informal care manager. The divorced 67-year-old lives in a remote countryside villa in the Oberbergische Kreis region in Germany. The mother of an adult son knows what it means to depend on others and how important it is to remain in control over one's own life. Charlotte walks with the help of a walking stick since she had a life-threatening accident when she was 17, which bound her to the hospital for an entire year. The time she spent in the clinic taught her the importance of solidarity, positive encouragement, and the difficulties of participating in one's treatment plans.

> "They always gave me pills I didn't want to take. I told them, I will not take them, I do not want them, there is no need. But despite my insistence, they kept handing me the pills. And so, I gave them to my mother who took them home in her bag."

Despite her disability, Charlotte managed to finish high school, graduated without delays, and later studied adult psychology. Working part time in the hospital, she specialised in non-violent communication, competence training for older adults and cognitive performance disorders. For almost three decades, she has worked as a crisis interventionist at the geriatric wing of a hospital as an interlocutor between doctors, nurses, patients, and their families. Additionally, she started to give classes to nurses and health and care personal, where she emphasises a resource-based approach to health that highlights agency and equality. Rather than focusing on what is lacking, she looks for abilities and thresholds and uses the patient's substance and means to regain strength.

> "I look at the whole person and not just at the holes in the cheese. That is my metaphor. I see the substance that is there, otherwise no hole can form. The doctors and the medical professions are more interested in how to plug the hole. And I rather observed what was going on around it, so that the hole might become smaller or more bearable."

In her professional life, Charlotte stands up for individuals disempowered by health systems. She works towards thorough transformations in hospital communication and stresses the need to address these issues on a political and systemic level to evoke change in institutions governed by strict regulations and power hierarchies. In her personal life, she experienced yet another facet of the health and care sector as for the past four years, as she built a network of care to manage the care needs of her now 99-year-old mother. Faced with the declining strength of her mother approaching her centenarian year, Charlotte has become the coordinator of her daily needs and administration of 24-hour care to maintain her autonomy. The difficulties, she points out, are to find the right match and for all three – her mother, herself and the fulltime

carer who lives in her mother's house – to get along. The biggest challenge for Charlotte was to accept the reversal of the parenting role, which forces her to make decisions without her mother's approval.

> "At the beginning, that's when I first noticed that I was getting into the role. I actually want to parent my mother, which is not possible, that was a reversal of our relationship, which was previously equal. And equal on the adult level. And then came my caring and sometimes I miss being the child."

In March 2021, three months after our last interview session, Charlotte's mother passed away, just two days after her 100th birthday. In an email, she explains that "the many months leading up to this point were very, very exhausting for all of us, so we are all redeemed. My Ma looked beautiful in death, I was very capable of letting her go."

6.4 Respite Care and Peer Support

While networks and professional support help in the day-to-day handling of care, not all older adults are in a position to distance themselves from the process. Especially those who live with a spouse in need of fulltime care, often struggle with the emotional burden of witnessing their partner's suffering and decline. Signe is a case in point. For four years, the 80-year-old mother of two sons has been a full-time carer of her husband who was diagnosed with Pick's disease, a rare but severe form of dementia. In the beginning, Signe only became aware of strange behaviour in her husband, who stopped responding to questions and became increasingly absent minded. As Signe had no previous experience with older people, she didn't quite know whether what happened to her husband was outside a normal process of ageing and doctors initially dismissed her concerns. Feeling that something was wrong, she and a network of friends and relatives searched for additional diagnostic options. Clarity came from the nuclear research centre which finally helped her to put a name on her husband's personality changes. After that, it didn't take long for his illness to fully manifest.

> "You know, you observe consciously how little by little the personality and the organism deteriorate. In the end, even peristalsis doesn't work anymore."

Trying to understand what she was dealing with and how to best handle the situation, she approached a friend who was a trained nurse to learn techniques of caregiving practices and sometimes asked neighbours to help her in moments of need. "Most everyone is happy to help, you just have to ask nicely". Additionally, she started doing research on the internet, attended courses and conferences, and later shared her own practical knowledge to forums and blogs.

Signe's experience exemplifies the importance of peer-to-peer support that many gerontological studies have pointed to. Support groups, including community-based

exchanges and professional training courses, or modern digital communication channels empower affected individuals – especially those with less common illnesses or disabilities – and provide advice or simply emotional consolation. The feeling of solidarity and connectedness provides comfort when coping with the pain of the situation. Additionally, participating in these forums, in community learning and educational meetings, whether in person or online, give back a sense of purpose, as informal caregivers can share their accumulated knowledge with others in need. As Signe puts it,

> "So I have to say, when people realise that you need help and you speak to them, you always find them. It is worse afterwards, when you are alone, then the distance is different."

The story of human resources manager Alberto (71) presents a similar point. His wife, who worked in the chemical industry as a social worker, was diagnosed with Alzheimer's disease about 15 years ago. Three years ago, she was institutionalised because of the worsening of her condition. Until then, Alberto assumed the main role of informal caregiver of his wife, becoming the main mediator between his wife, their immediate and extended families, friends, as well as public and private healthcare providers. The role of informal caregiver, especially the mediation with health care providers (e.g., neurologists, therapists, family doctor, pharmacies), was facilitated on the one hand by the support provided by the Portuguese National Association of Alzheimer's disease, and on the other by Alberto's high digital and health literacy. Using a computer and a smartphone, Alberto sends emails to doctors to describe the disease progression, his wife's behaviours, to share problems and challenges, and to ask for advice. He also shares information about his wife with family and friends and searches for more information about the disease.

Caregivers often have to balance their daily routines and accommodate the needs of their dependents whilst also remaining attentive to themselves and their own needs. The challenge then is to think about ways for community care and digital technology innovations to support older adults in their caregiving roles so that they can remain a caregiver and still make room, without guilt or anxiety, to take breaks and enjoy their hobbies, social contacts, and times of rest to maintain their own health and life quality.

Caring for her husband was a full-time job which required Signe to put her own body to use for helping her husband on a daily basis. Tired and run down, she realised that more professional services were necessary and that she was in urgent need of a break to rebuild her strength. To finance what is commonly called 'respite care' – in Signe's case an allowance to fund a short-term institutional care stay once a year – she sent an application to re-evaluate the level of care allowance her husband received. As part of the process, Signe had to keep a care diary. "With all the trouble you have with such care, write down for four weeks from morning to evening how you were needed." Then the appointment came, the MDK (medical service of the health insurance organisation)

came around, it was a young woman and Signe showed her all documents, including the diagnosis and the care diary she had kept. Without even looking at them, the woman told her "I don't need that. I get a first-hand impression! After all, we are no longer in the GDR." Agitated, Signe continues, "the woman went to my husband as he was sitting, smiled at him friendly 'Stand up.' He got that, so he got up. Then she classified him as care level 1." Disregarding the informal caregiver's knowledge and participation, the evaluation into the lowest level of care allowance did not facilitate the right to respite care. Fighting the clearly wrong assessment, Signe appealed, went through the process again and was finally given the correct care level and allowance six months later. Two months after her husband had passed away.

Our case studies demonstrate the need for more participation and empowerment of informal caregivers. To manage the needs of their relatives, they would benefit from improved access to services and faster processing of allowances through minimised and simplified administrative procedures. Application processes are often long, and evaluations often misinterpret actual needs. While revisions, such as in the case of Signe are possible, they might come too late to meet the needs of the carer and care recipient. It is important to improve these procedures to ensure that caregivers can continue their care practices whilst maintaining their own health and wellbeing.

6.5 Care Across Generations

The population aged 65+ is the fastest growing sector in European societies. Improved medical care, living conditions, and management of infectious disease all contribute towards longer longevity, much of it in relatively good health, though with a resultant rise in chronic care conditions and multimorbidity. Health and social care structures struggle to cope and discourses focused on 'burden' replace ideas of 'solidarity' in some neoliberal systems and populist media. Reliance on unpaid family care plays a critical role in care provision, with informal carers saving individual European States many billions of euros in care support costs. This includes intergenerational care where the assumed 'middle' is assumed to care for dependents at either end of the life cycle. The concept of 'duty' or 'returning the favour' still prevails and plays an important part in care giving.

Problematising such generic narratives embodied within the burden discourse or evocative terms such as 'age timebomb' or 'demographic tsunami', our participants remind us that older adults themselves play a key role in care provision and not all caregiving is from the younger to the older generation, nor does the roles of parents and children, which assumes a reversal of roles and reciprocity of care during the lifecycle, always take place. In ideal circumstances, the younger generation grows out of the need of their parents' care, but social, financial, and medical conditions can also create contexts, in which ageing adults remain or resume coping as primary care facilitators for their offspring.

Such is the case for Laura, 69, and Max, 70, who we met in earlier chapters. They live in Dresden in a beautiful house with a big garden. They have two daughters, the older settled nearby their home, and the other 500 kilometres away, with her husband and two children. Laura struggles with joint pain and her knees, but the couple is very active and independent. Max still works in the company he built, engages in volunteer work for young Muslim migrants and organises hiking tours for older adults. Laura, whose own grandchildren live to far from home for her to mind them regularly, decided to help other families and does some babysitting for three families in return for a small payment.

While Laura and Max are content with their life and enjoy social activities, they also struggle with the burden of caring for their first-born daughter who has suffered from anorexia and bulimia since the age of 15. "Of course, we would have imagined life a bit different." Worrying about her wellbeing and survival has become part and parcel of the couple's life. For the past 27 years, they engaged with treatment options, driving their daughter to hospitals and rehabilitation clinics. A few years ago, they even had to install a legal guardian to control their daughter's decisions and finances, noting that "bulimia is a money-eater. Our daughter has not one penny left in her account." Max and Laura learnt to handle the system: how to apply for care allowances, ask for help, and keep the emotional distance they need.

> "Still, it is hard. We always worry about her; she needs us every day. I don't know what will happen to her, once we are no longer. You can't do more than hope."

Rosa from Portugal also knows what it means to carry the burden of care for the younger generation. The 75-year-old woman grew up in extreme poverty and all her life search for better living conditions, particularly through hard work. Rosa, having migrated from a rural area to a semi-industrialised city, has always been a public employee, with a minimum salary. Her husband was also a public employee, sometimes working 'on the side' for extra money. They bought a house and saved some money that allowed them a life "without shortages". However, during her life she was never able to afford any "superfluous" expenses such as holidays, cultural consumption or higher education for her children. Nowadays, Rosa is retired and a widow. Following the death of one of her daughters, her daily life is divided between caring for the children of her deceased daughter and supporting her living daughter who lives in the main building next to the annex of the house she now inhabits. Unfortunately, despite her continuous support and efforts, Rosa has already been a victim of domestic violence by one of her grandchildren, who is diagnosed with schizophrenia.

These two case studies demonstrate a pattern of challenges faced by many older adult caregivers. Being in the role of an informal care giver in all its manifold versions, circumstances, and duties, comes with a range of obligations and emotional and

physical stress. Where older adults care for the younger generations the additional worry about the future plays a significant role. Knowing that the time will come in which they will no longer be there to support the care recipient is a considerable burden and concern. Certainly, stories such as Eleftheria's also demonstrate such feelings. Planning and building care networks, as well as mediating professional and institutional care are key to engaging with caregiving across generations.

6.6 New Beginnings

The role of informal caregiver is often time consuming, tiring and limiting. At the same time, however, for many of our participants it provides purpose and meaning; a sense of 'being needed'. Informal caregivers, willingly or not, often commit to the caregiving role to a degree that also reduces their own social life and network. Years, in which their duties keep them from regular social and leisure visits outside the household, from sporting activities or volunteer work, may carry an associated danger of isolating the caregiver from their friends and other societal involvement.

New challenges arise when the situation changes, for example when the dependent partner moves to a care facility or one's parents or spouse passes away. When the need to provide care no longer exists, older adult caregivers often struggle with a sense of loneliness and a loss of meaning combined with an increased awareness of older adults' own declining health. Now on their own, mourning and lack of purpose may be amplified by the pressures to adjust to a new lifestyle. Such moments of transition may elicit reflection on one's self-identity and an active reconfiguration of daily routines. For some, taking on new family commitments such as grandparenting, committing to volunteer work and actively engaging in community networks and social and educational institutions for older adults are strategies for recreating purpose and sociality.

Signe, who as described above, cared for her husband so intensively has gone through the experience of starting afresh after her husband passed away after four years. Once the duty of caring for her late spouse no longer existed, a feeling of emptiness took hold of her. She describes the experience of coping afterwards.

> "And then I started… I had a lot to pay off with the house and so on… but my mum was 88 at the time, and she must have thought that I would now give priority to her. But I thought I'd had enough of caring for a while. My work has always been very important to me and so I went to the Senior's Academy to see if they had a job for me. And from then on [laughs happily] I'm in the Seniors' Academy – first they put me in charge of public relations. Just imagine, I've never had anything to do with public relations, neither at the pharmacy nor at work. And then I went in and made the best of it."

To find new meaning in her life, Signe approached the Seniors' Academy in Dresden where she now works as the PR manager. By actively taking control over her everyday life and creating a new sense of purpose, Singe managed to rebuild a new social network and meaning in her life. The availability of institutions for older adults that not only "entertain" but also ask senior citizens to actively put forth their own capabilities and skills is therefore vital for a high quality of life at the later stages of the lifecycle.

6.7 Conclusions

Giving Care defines the lifeworlds of many older adults. While, in the prevailing discourse, senior citizens are often depicted as the social burden of an aging population, dependent on institutional, family, and medical support, the scope of their central role as social and cultural actors, as volunteers, child minders and babysitters, community supporters and first responders in home care systems is little recognised and seldom appreciated. Yet, older adults often play a key role and become the most important facilitator in processes in which others need help or lose their independence.

This chapter has identified five patterns of needs and potential relief (technological and otherwise) from our rich data for consideration.

First, caregiving is time consuming. Social exclusion, physical and mental exhaustion arising from adjustments to the needs of the care recipient, are a real danger in the process of informal care giving. Respite care, community networks and monitoring devices need to be made available to allow caregivers opportunities for leisure activities, meaningful breaks, and emotional and physical rest. Additionally, social activities often deteriorate in a period of prolonged caregiving. To prevent loneliness and isolation during this time and even more so, once the care recipient has passed away, neighbourhood support groups and networks of care are essential and help to reintegrate the surviving older adult to stay connected, retain a sense of purpose and find new avenues of daily activities under changed circumstances.

Secondly, smart home technologies to monitor patients – especially those suffering from neurodegenerative diseases – may assist in home environments, such as monitoring and alarm systems that guard doors and kitchen activities that may afford some relief to informal caregivers, particularly those living with dementia sufferers.

Thirdly, providing digital and physical social spaces for exchange of knowledge and experience gained by informal caregivers and opportunities to discuss frustrations and successes are highly beneficial and valued. Online forums for peer-to-peer knowledge transfer and especially understanding how others have overcome challenges, can help those providing care cope better with the emotional burden of caregiving.

Fourthly, facilitating better and more centralised points of contact and information material on care support as well as training in physical care practices are required.

Learning about particular health conditions and available financial support is key to assisting informal caregivers. Finally, gender inequalities and the disproportionate burden that falls on women. Engagement with the topic of care must entail an effort to integrate everyday life and "thinking from women's lives" (Harding 1991) to address women's role in social reproduction in later life (Taylor 2014). Gender therefore needs addressing to ensure the financial, emotional, and physical wellbeing of the care recipient and the caregiver alike.

6.7.1 Insights and Reflections

Considerations for policymakers, solution developers, and service providers:

- Despite being seen mainly as care recipients, older adults play a crucial but poorly recognised role in providing care. Indeed, the care provided by older people is very often central to keeping a care ecology viable. What can be done to recognise these contributions and change the stigma of older people as a burden and non-productive part of society?

- In this chapter we observe that a lack of support for informal care givers often alters existing relationships, challenges older adults physically and mentally, and might lead to isolation and loneliness. What opportunities can be made available to utilise or create embedded networks of effective community care to lower the negative impact of care practices on the informal caregiver?

- Given that older adult care givers develop expertise through the practice of caring, how can they be empowered to meaningfully participate in care decisions in an effective and timely manner?

- This chapter demonstrates the essential function of older adults as informal caregivers in maintaining a sustainable care ecosystem. This insight highlights the need to keep them involved in our thinking about care and to empower them with support services and tools and ensure means of self-care to prevent exhaustion or isolation.

- A sense of purpose is valued by people of all ages. Informal caregiving can provide a sense of purpose and involves the development of surrounding support systems. When care is no longer required, what supports can be made available to assist a smooth transition out of informal caregiving smoother?

FORMAL CARE WORLDS – RECEIVING CARE
Chapter 7

Chapter keywords: Care, Hospitals, Nursing Homes, Obesity, Communication in Health Care, Empowerment, Patient-Centredness, Dependency Steps

7 FORMAL CARE WORLDS – RECEIVING CARE

ALBERTO

For 15 years, Alberto (71) in Portugal has been the primary carer of his wife Maria who has Alzheimer's disease. In this task, he has been supported by their daughters, the National Health System (from primary care through medical specialists), and the Portuguese National Association of Alzheimer's disease. Additionally, he paid for private therapists for cognitive stimulation for Maria.

Maria is now in a care home, but Alberto continues to support her through different care activities including regular visits, both alone and with family and friends. During the coronavirus pandemic this in-person support became limited to one 'socially distanced' visit per week. Maria's care is also bolstered by regular communication between all members of her social network, and, through this contact, Alberto became sufficiently familiar with communications technology to maintain contact with and coordinate Maria's care network, using platforms such as WhatsApp, Skype, and Facebook. He also shares text, images, videos, and audio in this fashion.

At 71, Alberto is also successfully managing various age-related conditions, but, after he injured his left leg in a recent fall, there was a genuine concern, in both his medical team and across his network, that Alberto himself might become infirm. Thankfully, he has managed his recovery well, following medical advice to walk for at least one hour a day, eat a balanced diet, and get sufficient sleep. In short, Alberto has been a good patient. He continues to live independently and has even accepted a smart bracelet for monitoring his sleep patterns and physical activity, information that is shared with his General Practitioner (GP) and other health professionals.

As important as these supports, Alberto explains that he also has an 'old friend', a GP colleague from his working days, as well as a doctor in the family, his nephew who is an ophthalmologist, both of whom provide him with healthcare options and news about useful innovations. This relationship with medical experts is a great advantage in navigating the healthcare system and gives Alberto confidence to discuss aspects of his treatment with his doctors. He often calls them for advice before contacting health providers from the National Health System.

DANAE

Danae is a retired 69-year-old widow living in a village in central Greece, close to her married daughter. Her son lives with his wife and her two grandchildren in a nearby village.

After living in Germany for many years, Danae, her husband and children returned to Greece, setting up a small family run business on the ground floor of their home where she worked as a cook. After her husband's death, Danae retired and converted this space into a place to meet her friends, have coffee and to make sweets and pies for the ladies' club. In retirement, she says "I love cooking for family and friends". Unfortunately, since the onset of COVID-19 she can no longer host these meetings.

These days, Danae lives alone on the top floor of her two-storey terraced house. Climbing the stairs has become a serious challenge. Obese at 120kg and a smoker who enjoys ten cigarettes a day, she has been diagnosed with knee osteoarthritis and suffers from lower back pain for which she takes daily painkillers. After a few recent unpleasant falls, Danae developed a fear of falling. As a result, she decided to limit her movements. This bothers her because it prevents her from going on trips to monasteries with her friends.

Danae also suffers from multiple serious health problems. She has been diagnosed with heart failure, atrial fibrillation, hyperlipidaemia, obstructive sleep apnoea and depression. Every month she visits her GP for her medicine prescription. Although her doctor advises her to stop smoking, control her eating and to exercise, she doesn't follow the medical guidance. Danae also pays an annual visit to a cardiologist and a pulmonologist. Because of the obstructive sleep apnoea, her pulmonologist prescribed a CPAP (Continuous Positive Airway Pressure) machine, which she has been using now for four years to improve her sleep quality.

Danae is well aware that many of her health issues could be reduced if she could lose weight. She is also at risk of developing diabetes in the future, which will further complicate her health condition. On several occasions, attempts to lose weight have been unsuccessful (see also Chapter 2, Social Worlds). After trying on her own, Danae resorted to spending money from her pension to secure the services of a dietitian, but she has still not managed to meet her weight loss ambitions. This situation is likely exacerbated by her reduced mobility due to fear of falls.

Things were further complicated in Danae's life when she experienced a serious episode of depression three years ago following the deaths of her husband and sister. For a long time, she did not go out of the house, she was not in the mood to do the housework, nor did she meet with her friends. She visited a psychiatrist who diagnosed her with depression, and since then, she has received medication.

When asked how technologies could assist, she wistfully suggests that she would like to see "an electronic box that could check all my health problems and inform me of my health condition". As important as advances in how to monitor and manage her chronic diseases and health conditions at home clearly are to Danae, her lived experience also reminds us of the value of technologies that could help bolster her confidence

with walking and movement as well as helping identify, track, and encourage her progress with weight loss goals.

Despite these accumulated physical and mental health problems, Danae is an energetic person who loves life. She regularly volunteers for her church charity and she likes knitting. She continues to drive and enjoys short trips with her friends in nearby villages. Looking into the future, Danae wants to be in good health and dreams of being able to travel all over the world.

7.1 Introduction

We begin with two vignettes of fairly independent older people, both living at home, both close to family, connected to local social circles, and both regularly in touch with doctors, nurses, and other professional healthcare providers. We use these two cases to provide an opening for our discussion of how the formal or professional healthcare system looks like from 'below' and how it is experienced by some older people. One, Alberto, is seemingly managing very well, and the other, Danae, seems to be near a crisis, perhaps even near a dependency step, where she will no longer be able to manage at home without significantly more formal assistance, or perhaps, not be able to manage at all outside of an assisted-living facility. In most medical and policy discourses, Alberto is praised as a 'good' patient – receptive to professional care and medical advice and embracing new technologies that help that advice work. In contrast, Danae is seen to be more problematic, not able to adhere to health advice (even that which she privately contracts) or change her "lifestyle" in a meaningful way, all the while sliding into a cycle of depression and feelings of personal failure. Even their approaches to 'technology' are at variance. Alberto uses available technology in his life and in his pursuit of his treatment, as well as to organise the care of his dependent wife. Meanwhile, while Danae expresses a general interest in technology, she seems to be longing for an unrealistic "magic box" that would manage (and ameliorate) her multiple, intersecting chronic health issues, allowing her to suddenly be "healthy".

The two cases also represent the endpoints of dreams and the anxieties of many policymakers, health-economists, and media outlets in their framing of how (or even if) health systems can 'afford' an ageing population. The 'Old' we are told, will 'blow up' health budgets. As their numbers grow and as lifespans increase, there will be more and more chronic conditions to manage by public health care systems already struggling in many countries with budget constraints and wait lists. We are also told how impossible this 'burden' will become with the ongoing expansion in the number of older people with complex, chronic conditions, often compounded by psycho-social issues. This is not a trivial issue. The costs associated with providing treatment and support for chronic care are one of the main drivers of the overall costs of healthcare, which currently hover at around 10% of the entire European Union Budget.

Table 4 Current healthcare expenditure, 2018 (Eurostat 2018).

Percentage of GDP given to Health Costs.
EU Average 9.87%
Germany 11.47%
Portugal 9.45 %
Finland 9.04%
Spain 8.99%
Italy 8.67%
Greece 7.72%
Czechia 7.65
Ireland 6.93%

Promotors of technology in healthcare, on the other hand, often offer visions of a more hopeful world where new devices, robots, and/or apps result in experiences of ageing similar to those exemplified by Alberto or better put, that technology can help to change the 'Danaes' of this world into 'Albertos' using accessible technology, allowing older people to better control their lives and wellbeing. This popular vision, reflected in many National Healthcare strategies such as Ireland's *Slaintecare Programme* focus on keeping people healthier and happier at home and in their communities, bringing more care and supports into the home and neighbourhood when needed, and reducing or relieving demand upon overstretched hospital and institutional care structures.

7.2 On Care

Both the anxieties and hopes outlined above, require us to come back to definitions and delineations of types of care. Many of our research participants have regular connections to the formal care system in their respective countries, insofar as they manage a range of chronic conditions with a wide array of professional support, funded by varying combinations of public and private sources. For some, these connections already existed for decades going back to accidents or injuries from their youth, and many of the rest have experienced acute conditions in older age. Others have been far more fortunate, managing common chronic conditions, such as high blood pressure, with little connection to the formal care system beyond their GPs. In nearly all of these cases, however, they have experienced some mix of the "formal" system of Health Care Professionals (HCPs) in association with "informal" carers, networks, and practices (for a detailed discussion on informal caregiving see Chapter 6, Informal

Care). A recent EU Report (Zigante 2018) has offered an inclusive approach to conceiving care systems that better reflect the actual composition and functioning of interconnected care systems, with different clinicians and healthcare providers sought for outside of the home, and, depending on the jurisdictions, state money going into the home to compensate for the time of intimates delivering care.

If, in the real world, however, forms of care are always interrelated, then it is also true that they often interact haphazardly. This interaction is made even more complex because the balance of "formal" and "informal" tends to be dynamic, as acute incidences improve (or worsen), or as chronic conditions require more care as individuals experience multiple issues resulting in greater levels of frailty. In addition, like many older adults, Alberto mentioned above, combines the roles of being a provider of "informal" care to a loved one, a negotiator of access to "formal" care for her, and a recipient of "formal" care for his own (multiple) conditions.

Older adults are not just most commonly the primary "informal" carers to intimates, such as spouses, friends, or siblings, but many also care for very old parents. Furthermore, as we have seen in previous chapters, they also can, episodically or in longer-term, be the source of such care for younger generational cohorts, as their children with chronic conditions move into middle-age, with few other means of support, or as their own children cope with children requiring care (for more on 'Care across Generations' see Chapters 4, 5, and 6). These lived realities make the divisions of "formal" and "informal" little more than a heuristic to think about care from the perspective of the healthcare system (usually with an eye to cost). If such heuristics get mistaken for actual divisions, not only is violence done to the lifeworld of individuals, but very often precariously balanced care situations can be destabilised, at the cost of reduced individual well-being and vastly increased healthcare costs.

7.3 Hospitals at the Centre of Formal Care

The hospital is the most obvious institution in formal care, the place where serious illness and injury are addressed. It is also the place that often emerges as a marker of increasing frailty as visits become more common. D3.1 SHAPES ecological organisation model covers the more macro data dealing with how hospitals and professional care broadly exist in the various national medical systems in which our informants are enmeshed. D3.1 analyses many of the challenges posed by geography and financing models to access of services by older people, so we will not be recapitulating this data here. Instead, in the following sections, we chart how hospitals and professional medical systems appear from the perspective of older adults engaging with them. From this perspective, the hospital is often experienced as a space of alienation, where both language and agency are transformed, generally to the detriment of the older person. Not surprisingly, the hospital often becomes a lightning rod for complaints.

As described in Chapter 6, Charlotte (67) from the Oberbergische Kreis region studied adult psychology at the age of 38 and later specialised in geriatrics and patient-advocacy. Working part time in the hospital up to her retirement, she functioned as an interlocutor between doctors, nurses, patients, and their families, and expresses the disappointment she often felt with the way language was used in this environment, noting that, in contrasts, she chooses to not "use a pathology-oriented language, but rather resource-oriented language". Recalling her experiences, she describes the language used in the hospital as warlike or technological. She recalls:

> "Nurses' rooms are [called] bases, and hospital beds are [like] parking lots. People have 'medicines on board', and there is a glut of old people. It is all characterised by an attitude that I don't think is conducive to a prosperous coexistence."

Furthermore, upon arrival and during the triage process, patients are regularly stigmatised and labelled in quick judgments. During the morning meetings when staff discussed newly admitted inpatients, Charlotte remembers hearing sentences such as, "Watch out, X's son is a colleague. They are the really difficult ones, they know everything better" or "that's a sweet granny" or "daughter is a teacher"; but also "patient is aggressive", or "we still have to tame them". Such descriptions come across as pejorative, judgemental and prejudiced, and have the potential, intentionally or otherwise, to position people as 'problems' or contribute to decisions about resource allocation and priorities. Contrary to a humanistic approach to patient care, such language and characterisation can stick like a verdict and reduce coequal communication, the quality of care and patient empowerment, or, as Charlotte puts it,

> "If you're unlucky, you can keep that label for the entire inpatient stay. Stamped like that, how am I supposed to get better?"

Seeing 'unhealthy' communication patterns in the hospital, Charlotte then applied her expertise and interest in non-violent communication not only to her workplace but also started to give classes to nurses and health and care personnel on communicating with patients, which she continues to this day despite her official retirement. For the past four years, Charlotte has additionally taken on the role of care manager for her now 99-year-old mother, organising and conversing with fulltime professional home carers, a network of supporters, and everything else for her. On the subject of health care, she tells us that her trips to the hospital are to her like "travelling to China" to mark the radical changes in language and relationship expectations that she expects to encounter in the institutional setting.

While few were as eloquent as Charlotte, there was a widespread sense among our 94 case studies that navigating hospitals and other formal care systems can be challenging, above and beyond the health implications being addressed. Medical language can be intimidating, and interventions and their risks are not always easy to

understand. Understandably, information is often parcelled, controlled, and exchanged in an asymmetric manner, especially before a diagnosis or treatment plan is fully determined but it is also sometimes poorly articulated and impatiently delivered at a time of high stress. Some research participants talked openly about the dangers of disagreeing with medical personnel such as Monica (78) in Northern Ireland who argues that "retribution has fallen on my head from complaining".

A recipient of a great deal of medical attention and surgical operations over the years due to a deteriorating spinal condition (see opening vignette in Chapter 3, Moving through the World), Monica always felt comfortable in hospital and rehabilitation centre environments. That is, until one day when she was wheeled into an operating theatre in a private non-teaching hospital to find a number of teenage girls in attendance without her permission. She made an official complaint, and the anaesthetist was heavily sanctioned. Unfortunately, during a subsequent hospital stay for an 11-hour operation, she recalls feeling abused by one of his professional colleagues.

> "The anaesthetist who came to talk to me, I had never seen before in my life. She came to my bedside, pulled the curtains around and she was horrific in her treatment of me. In fact, when she left after half an hour and I was shaking, one of the nurses in the small ward I was in said to me 'what did you do to rattle her cage'? I said, 'I've never seen her before, I've never met her but she's my anaesthetist'."

A daily user of morphine due to chronic pain issues, she believes the amount of morphine in her pump was inadequate for her body's needs so she was in a great deal of pain after the operation. During her long hospital stay she also experienced unusually detailed scrutinisation of her prescription list and criticism of her diazepam use, which had serious implications as it eventually led to her being 'struck off' by her GP.

The hospital can also mark the end of one phase in life and the start of another, more dependent one. Psycho-social supports to help people understand and cope with such transformations are often lacking. After his stroke, Bert (70) received comprehensive care to help with his medical needs and improve his physical functioning. His sense of self-efficacy declined however, and his alcoholism, chain smoking, and loneliness deepened until a year later he finally had a major fall that almost killed him (see Chapter 3, Moving through the World, for details).

Formal care systems can be challenging to access, and potentially alienating once inside. It is telling, for example, that, as competent a patient as Alberto, still relies as much on personal connections within the formal health system such as family members who are medical doctors, as his own technologically enhanced experience and abilities to successfully navigate its complexities for both himself and his wife. This theme of familiarising a system through personal relationships appears in several

cases in our data. This tactic, found across systems as diverse as those in Germany, Italy, Portugal, and Finland suggests that 'barriers' are not merely those marked by experience-distant metrics like geography or finance, but are significantly experienced in so-called 'softer' ways.

Patrizia (65), in Italy, despite having worked in the health system during her career, still finds relationship with her doctors' problematic. Formal caregivers in the Public Health System experience high turnover rates, so she finds trusting relationships are difficult to build up. She describes herself as very anxious and tends to have many different health issues connected to her psychological state. Almost four out of five of our informants relied on the public system for their health care, so this turnover of personnel issue is potentially a serious one and adds to older adults' experiences of the Hospital as an alienating and disempowering space.

Attitudes towards and perceptions of different political and health systems are influenced by historical as well as personal experience, as seen for example, in critiques of 'public' and 'private' healthcare distinctions by older adults who grew up and lived in the former German Democratic Republic or in Czechia. Signe (80) from Saxony regrets that, with the reunification of Germany, all GDR structures were dismantled without differentiation, even though the GDR's health and educational systems had much to offer. With the reunification of East and West Germany, institutions such as the *Polikliniken* (multifunctional clinics of the GDR), in which various specialists kept their practices under one roof, have been dismissed as inefficient socialist structures. In the past 10 years, however, ostensibly "new" concepts of medical centres have returned to Germany and elsewhere in Europe facilitating greater integration and promoting quick, cheaper, and more efficient public health care services that are closer to the community level of health care.

Furthermore, with health structures run by the state, Signe suggests doctors would be employed on a regulated salary thinking only about their patients' needs. 83-year-old Heinrich who lives in Dresden echoes such opinions asserting that "Doctors should not have to be businessmen" - with much time in capitalist health and care systems spent on getting 'the numbers right', time is better spent on patient consultations as the core expertise of the medical staff. Similar views were also expounded by Christos (69) in Greece who argues that though he believes most doctors, especially 'young ones', more than earn their salaries, there are also others who are "snobs", greedy or corrupt. He describes meeting a doctor who asked for payment for everything and another who "wanted you to buy a t-shirt from one specific store". He is also suspicious of the motivations driving certain medical decisions:

> "Last year I went to an Open Care Centre for the Elderly to visit a doctor and asked him to prescribe my son's medication and he wanted to prescribe a different medication. I disagreed with him, because my son has taken this particular medication for many years. He told me that if I wanted him to

prescribe the medication, then I should comply with and accept the medication he recommended. I think that the reason he insisted on changing the medication was because he had a contract with a pharmaceutical company. To prescribe specific medication. I hope this is not happening anymore."

This section has briefly provided insights into experiences of community dwelling older adults when interacting with hospitals. Problematic aspects mentioned by our participants include staff turnover, language and communication difficulties, navigating complex and often disjointed health environments, insufficient psycho-social supports, and ongoing fears over disease control. Other issues that commonly emerge when discussing negative hospital experiences include lengthy hospital waiting lists and queues, the quality of stay, access to 'step-down' units, financial assistance, home care support and other resources following or as part of the hospital discharge process. Some of these issues have been explored in other chapters in this report and will be further elaborated in future publications.

The aim here has been to articulate some of the gaps in formal care provision identified by our participants, but it would be misleading and remiss of us to neglect the many positive stories we also heard from our research participants about their experiences with the institutional healthcare structures in their countries. For example, Madalena (73) in Aveiro recalls the exemplary treatment she has received in the past, especially given the abuse and stress that medical staff can experience in the course of their jobs. She notes that whilst many people complain about hospitals and doctors, very few give compliments. Monika (83) in Czechia, reminds us of the small and unexpected kindnesses often found in the quiet everyday moments of the hospital life. She recalls the boredom of a four-month hospital stay. Her hobby of knitting kept her "going for a long time" but the only television was in the corridor and even on crutches she couldn't manage the walk. Assistance came from an unofficial and unexpected quarter.

> "Well, there was a cleaning lady who used to go to the library in the hospital, she borrowed books for me, so I also read. I always read until nine o'clock in the evening before the lights went out."

Returning to Germany, Hannelore (76) told us about her experience of cancer treatment in Dresden. Overall, she found the service to be excellent, though in passing contributes the useful insight that one thing she would have liked more support with at the time was transportation to and from the hospital as she lives alone, and her family members work during the week. This minor issue aside, she is effusive in her praise about the service she continues to receive from a much-favoured doctor.

> "I have a doctor at the university hospital in Dresden who is a haematologist and runs a clinic there. I go to him twice a year because I once had an illness in his field, and that's for me - I could put him in a golden frame. He is a dream

doctor. Even though he is a highly specialised doctor, he takes everything into account with his patients, everything, everything. He knows after half a year, or has made a note of it, or takes a look at his records: 'Well, the last time you came to see me, you had a cold. Did that soon go away, or did it drag on for a long time? And how is it going now?' So he goes into EVERYTHING and reports and does. And the other day I was there, he says: 'Have you lost weight?' 'Yes, I lost a bit of weight', and then we discussed what the cause could be. And he says, you have to be careful – I am very slim – that you build up your muscles. A haematologist! And then he showed me exercises to do [laughs]. So, and that's a doctor, dreamy."

7.4 Other Institutions of Formal Care

Of course, there are any number of facilities between and around the Hospital and the Community through which professionals deliver care. GPs/Family Physicians and other primary healthcare facilities are usually visited more frequently and with less fanfare. In GP-centric systems, very trusting relationships and very bad ones can facilitate or hinder the notional working of the services at this level.

Rosa (75) in Porto enjoys visiting her local health service as it is not only free, but she likes the conversations she has with her GP. Likewise, 92-year-old Donatella in Italy feels fortunate to have had good relations with her family doctors, past and present, and felt she could rely on them to visit her at home if required.

> "It is good. I had Doctor S. for about twenty years, [he was] our family doctor. He came to my house when I had invited him, but also the doctor I have now will do it if I need it. If I need, he comes. I have his phone number and I can call him whenever I need, even only to ask for a piece of advice."

Hannelore's family doctor in Dresden also does house calls, but she is less generous in her comments about her GP than she had been about her hospital doctor, once again illustrating the importance of communication skills and 'bedside manners' for many older adults.

> "My family doctor is not the most positive example for me. I don't want to talk about her in a negative way, but she is very, very clam [uncommunicative]. And what really bothers me is that she can't look at you when she's talking to you, she always looks to the side. And then sometimes I have the feeling that she doesn't really take you seriously and only when you become very clear and very demanding does she more or less do something. But that's not recent, it's been like that for a while. But I changed to her five six years ago. I had a very good family doctor before, but she was very far away and didn't do house calls. So I thought that when I get older, I might need someone to come to the house. So

I changed to this doctor who practises nearby. Yes, but I couldn't build up such a nice relationship with her because she's not very approachable."

In many older adults' perceptions, the most problematic institution in the formal system is the Nursing Home. Whilst for some it represents a refuge offering temporary or permanent respite, especially following great challenges living independently, for others it looms threateningly ahead as a possible future (often to be avoided at all costs). Like a transitional space or waiting room for physical death because it is seen to confirm a kind of social death, and, to this extent, becomes a lightning rod for the worst feelings connected to the formal care system. As Madalena (73), in Aveiro, Portugal put it succinctly:

"Some old people's homes [nursing homes] are like warehouses. They treat them like children with those little songs, they put on for them. It pains me to see people doing those silly things that don't open their heads for anything. I don't know, something else, motivating them to live things."

Even temporary housing in residential or nursing homes, for instance recovering from falls or as a step-down from hospital care is seldom remembered with appreciation or fondness. The regimen and the lack of agency of these institutions seems to rankle the most. As 84-year-old Nikolas from Greece soberly put it:

"They keep you alive to get your money. It's better to go somewhere until you can eat and go to the bathroom by yourself. If you aren't well they must leave you for a week to die. It's preferable. I'll prefer such a nursing home where they'll take care of you until you can care for yourself, when you stop doing that they would let you die. I would prefer that 100%. In the meantime, people you are close to and family try to find the best solution so they choose a good nursing home. In the end, however, what they are waiting for is for you to die, where it's better to take you in order to receive care. And then they are waiting for your death. But in order not to let you die, instead they are torturing you forever and they are prolonging your miserable life."

Of course, not all of our informants shared such negative appraisal, at least insofar as residence in assisted living facilities goes. Evelin aged 80 had moved into an assisted living accommodation after her husband passed away so to have facilities close by and to have more social interactions than living on her own in her house in a remote village in the Oberbergische Kreis. She enjoys it there, but mentioned that those, who move to the retirement home adjacent to her living quarters, for example for health reasons, hardly ever return to their flats and live much less desirable existences.

This nuance of moving away from "home" into a more institutional facility comes from the same dynamics that make for the negative assessment of some hospital or GP experiences: older people feel their agency stripped while being objectified as a "problem to be managed" rather than a person to be engaged. This quality within the

acceptance of care in the lifeworld complicates axis of care delivery like the simple geography of care. To be sure, many older people express a preference for "living at home", but there is nothing about home, per se, that guarantees quality of care or quality of life. When social or emotional isolation mark the home environment, then an assisted care facility can be very welcome, as in Evelin's case (see also Chapter 8, Legacies and Future Worlds). But, when "care" comes at the cost of agency and with a sense of being objectified as a burden, it is experienced as profoundly alienating. It is more important, therefore, than any assessment of needs of older people, to understand the complex emotions, anxieties, and hopes that exist under seemingly simple terms like "home".

There are other (and older) formal care institutions than allopathic hospitals. The Spa, for example, was accepted by some as a worthwhile institution, say, as a space of literal (re)creation to recover from surgery. This is an institution administered by professionals who, despite working with slightly different logics, can fit comfortably with other healthcare professionals. Other forms of treatment are generally seen to be so far away from formal medical logics that they are labelled "alternative". Many users of alternative medicine, such as Xenia (66) living near Cologne, combine different therapeutic logics, a phenomenon Medical Anthropologists call *medical pluralism*.

> "I go to the dentist and I go to cancer screenings. That's what I do. And apart from that, I usually go to an alternative practitioner, until now, for these bone problems with my knees and so on. I've already been to an orthopaedist. I also had an MRI done."

The variety of health practitioners engaged in health treatments presents both challenges and opportunities to those concerned with theorising health systems and improving them with technology. Even the most ambitious Electronic Patient Record plan, for example, rarely imagines including the experience of alternative practitioners. It's perfectly feasible, however, to imagine forms of coordination with such practitioners, and it may well be that, at least for some older people, some forms of psycho-social interventions might be best handled through such therapists.

7.5 Covid-19 and Formal Care

The coronavirus pandemic shaped this project in several fundamental ways, not least in that it provided us much more time to investigate how the people we talked to understood health, sickness, and wellbeing. This longitudinal viewpoint is especially important because the pandemic added another level of complexity to accessing formal care. Care systems throughout the time of this research struggled with being overwhelmed by victims of the pandemic, while being terrified of producing Healthcare Associated Infection (HAI). Because of this fear, health systems the world over did all they could to keep older patients away. Just as Covid-19 reoriented the lifeworld and domestic life, isolating some older people as they cocooned or moved in with relatives,

the pandemic stressed every link of the formal care system assemblages. This caused challenges for most of our research participants, but it posed significant difficulties for those with disabilities as facemasks and social distancing made it especially difficult for the deaf-blind to communicate and access services.

Covid-19 also forced some worrying changes in treatment protocols. As Beth from Northern Ireland recounted her recent fall:

> Beth: Yes, [I fell on my] back. The bones between the two hips. That was dumb. I wanted to make a cup of tea for us, and as I was standing up just to get one of the pots the pots fell over and my head – I thought my head was gone!
> Interviewer: And did you spend time in the hospital?
> Beth: No, no. They just called the ambulance, and they came out and they left. The doctors don't come out now.

Like the rest of the world, vaccinations were welcomed by many and viewed with scepticism by others. Once again, personal connections within the professional system for advice, not always with ideal results, proved critical in 'domesticating' formal public health advice. As Barbara (64) in Czechia related,

> "No, no, no, no. We had a friend, a doctor, a neurosurgeon, and he was also already a bit old, and a little son was born to him, so we discussed it then, years ago, and the doctor said then: 'I would never get vaccinated for anything, for any jaundice, no flu, just as basic as you, the kids, as we were given, some vaccine, but nothing else.' And I still hear his words, and, moreover, when you sit down, just like that. I'm wondering, isn't it, so the research takes years to do something like that, right? After a year, such a quick release? I don't even know, well. I'm against it, I wouldn't get vaccinated."

The coronavirus in short, radically altered nearly all aspects of the formal health systems but understanding of medical advice about Covid-19 slid into familiar grooves of having trusted sources "inside" the system being seen as a reliable source of either care or information.

7.6 Conclusions

We have conceptually organised this report around the pillars of Purpose, Process, Participation, and Practice. Clearly, the purpose of any professional health system is dedicated to their clients recovering and maintaining wellbeing. Process, Participation and Practice can be more challenging hurdles, however. The care required to regain and maintain wellbeing is practically distributed between professionals and intimates such as family and friends. However, in most cases, but these networks, resources and silos are too often haphazardly organised vis-a-vis one another, and cumulative

changes, whether in terms of new acute incidences or worsening chronic ones, present challenges even to well-coordinated and managed services.

As explored in the previous chapter, such changes tend to stress the care structures provided by intimates, who often have to deal both with increased workloads in the domestic sphere and extra management issues outside the home, in terms of coordinating care with professionals. Practices in the formal system can also be experienced as alienating by older people, and, thus, participation in such processes become more difficult.

Process and Practice for care are necessarily dynamic in formal care systems, as the trajectory of any patient involves movement between different sections and care packages within that system. When these elements of the care system are at odds with one another, for example when professionals, budget and resource holders, and intimates seem not to share the same goals, problems occur. The trick is how care provided by professionals and care provided by intimates, or portions of the formal system more local to the older persons, can be made to better fit together. When these elements mesh, health systems work well, from the perspective of maintaining wellbeing and keeping costs under control as Susanne (85) explains:

> "Yes, yes, it works quite well. I'm in a family doctor's practice. They know me; they know what's going on. I had no problem getting a follow-up prescription for the first physiotherapy treatment. And that's all important and, if necessary, they also send the prescription to the pharmacy, where they also know me. And the pharmacy brings it to me if I can't come into town or something. So everything is well organised. Of course, we are a small town, it would be worse in a big city, but we are lucky here."

7.6.1 Insights and Reflections

Considerations for policymakers, solution developers, and service providers:

- Delineated lines between "informal" and "formal" care are not always clear cut. What opportunities are missed when we define care as informal and formal? How might these definitions be reformed to close unintentional service gaps that endanger the well-being of individuals while increasing healthcare costs?

- The failure to follow medical advice is complex and forces beyond the doctor and patient relationship are generally implicated. Social contexts, structural constraints, personal idiosyncrasies, and cultural misunderstandings need to be appreciated when assessing the effectiveness, and the willingness or ability to follow medical advice.

- Older people feel their agency stripped when being objectified as a "problem to be managed" rather than a person to be engaged. How might existing and new services allow for patient participation in their health management and a sense of control and ownership?

- How might care systems and technologies create a healthier symbiotic relationship between professionals and clients so that care recipients can meaningfully participate, and professionals can effectively serve? What opportunities are available for policies, devices, and emotional aids to better integrate medical participation of the care recipient.

LEGACIES AND FUTURE WORLDS
Chapter 8

Chapter keywords: Memories, Technologies, Change, Generations, Bereavement, Inheritance, End of Life, Advice, Agency, Control, the Future

8 LEGACIES AND FUTURE WORLDS

Donatella

Donatella is a 92-year-old widow from Bologna, Italy. Her husband died six years ago, after more than 50 years of marriage. She recalls how they first met, at an art exhibition in Venice, and had been together ever since. Donatella has two beautiful children and a family of numerous nephews. They all still visit and enjoy spending time with her, recollecting and sharing moments together.

Memories are an important part of Donatella's life. She fondly reminisces about the times when her husband was alive and when her children were younger. Donatella will often read a biography of her marriage written by her husband. She also enjoys reviewing old letters that her children wrote to them when they were at school. But above all, she loves to look at photographs.

Donatella has thousands of photographs covering all aspects of her life starting from her early childhood. Every day there is a moment when she sits on her couch and takes time to revisit her favourite images, evoking special memories. She does not always look at them alone. Donatella likes to share these photos with her family. Especially younger relatives oblivious of her earliest years. For Donatella, this activity is a method of describing who she is and who she was, not only in the current moment but throughout the entirety of her life. And it is a way for her to share her life's experience, give advice and explain to her granddaughter the meaning of love.

> "I always say to my girls ... especially to the youngest, I always say ... when a man looks at you like this, like mine looked at me, that's the "right one" ... It's a photo in the mountains, he has his hand on my shoulders and he is watching me! And it's a look ... loving, let's put it this way, that's it!"

Donatella's family recently gifted her a treasured item. They gathered all her images and uploaded them onto a tablet where she can now look at them whenever she pleases without wrestling with heavy albums. Donatella explains that she had been granted the possibility of taking her memories with her wherever she goes and can now show her photos to everybody in an easy and efficient way. Despite her advanced years, she made the effort to not only learn how this technology works but perfected her use of it. She knows how to move from one album to another, to enlarge photos and to rapidly search and locate what she is looking for.

> "I like to use the tablet much more than traditional albums, because I can sit on the couch and go through all of my photos. I know where to go, which ones I want to see. I can always have my photos next to me, to remember, looking at

my things… my memories. I can look at them whenever I want, and I can do it faster than before."

Having her photographs on her tablet is useful not only to ignite old memories, but it also reassures Donatella that her story – and her beloved husband's life – will not be forgotten when she is now longer here. "While he was writing the book of his life, my husband always came to me asking about information… I knew everything about his ancestors because I've got photos of his parents and uncles. So, I knew everything about his life!" While photographs can be lost and ruined by time, having all this material on digital devices allows her to leave a legacy or heritage to her family. She wants to provide them with the opportunity to know their roots and to continue building a common memory.

8.1 Introduction

Donatella's story makes us think about technology in a different way. Technological tools often focus on how they can facilitate action: how they help people exercise or excite body and mind, communicate with other people, watch movies, or YouTube tutorials, or get a service online. In societies and lifeworlds where the pace of life seems to get ever faster, we sometimes forget the importance of inaction. To remember, to pause, observe, listen and reflect. Donatella's use of the tablet represents this concept in a clear and touching way. For her, images carry meaning that let things "come alive". A way of creating, sharing and mutually experiencing a moment inside her past. She, like many of the other older adults in our research, has a treasury of valuable and valued memories and a desire to share with those ready to listen.

Memories form an essential part of older adults' lifeworlds and self-identification. Recollections of their childhood, education, family and work life, as well as their reflections on changing political and societal contexts have shaped who they are today and how they look at the world in general. Their experiences, knowledge and reflections are part of the legacy of a generation that saw Europe go from War to Peace, from a divided to a (largely) united continent, and from a life with few electronic tools to fully digitalised homes where the internet and technologies became a cornerstone of everyday practices. Engagement with the plurality of older adults' perceptions on transformations in community living, family life, material worlds, health care, and philosophies demonstrates that everyone is more than they appear at a particular moment in time.

In this chapter we examine the wealth of experiences of older adults, their philosophies, and suggestions for the future. Part one attends to the meaning of collective and individual memories, agency and empowerment and how, despite obstacles, they retain control and hope for the future. The second part engages with

the end of life, death, inheritance arrangements and the experience of loss and bereavement. The chapter concludes with a summary of the main findings.

8.2 Agency and the Meaning of Memories

People are marked by the memories they build during a lifetime. However, memories are created and fluid, not fixed and given (Rosenblum 2002) and the way we remember and feel about the past is shaped by how we interpret it from the present. Understanding habitual practices, socialisations and meaningful contexts help policy makers and solution developers explore how to successfully implement ideas and to understand some of the factors that could induce failure of product and services or why recipients might refuse "help". Two examples demonstrate the point:

Madge (82) from Northern Ireland lived a strenuous life in a rather unhappy marriage. The mother of three worked hard to provide for her children, especially since her husband had left her early in their marriage. Her husband suffered from alcoholism and was often abusive. Before he left, Madge had to care for both her husband and for her son, who needed support since obtaining a brain injury. Working up to the age of 67, Madge has always continued education and social engagements to enrich her life. Today, she reads extensively, runs a crochet club, and goes to church regularly. Upon being asked what she would change about her life, she said "Some things. You know, I used to say, I would have listened to my parents, and I wouldn't have married my husband." Thinking back, Madge would have wished for a more loving relationship, however, she also adds:

> "But then, I wouldn't change the children. They wouldn't have been the same if I'd have them with somebody else. That's the principle I apply to other things in my life as well: things wouldn't have turned out the same. Today I believe that all those tragedies and traumas that I have gone through made me the person that am."

The trials and hurdles of Madge's challenging past are made meaningful through her reflection of her ability to successfully raise her children. And even though nowadays Madge walks with a stick and sometimes falls over unexpectedly, which makes her feel vulnerable, she does not feel feeble. Her present work as a volunteer and the many challenges she went through in the past have empowered her and made her into the determined woman she is today.

For Giuliana (84), a Christian Italian of Jewish origin, the memory of overcoming challenges in life is a lesson in agency that turned her into an ambitious and emancipated woman. Giuliana lives in a beautiful flat in a top floor of an old apartment building overlooking Bologna. Born in 1936 she has much to say about fighting against the odds as she spent her childhood on the run and in hiding. Persecuted by the National Socialists, the family of eight was separated for years. All survived with the

help of the "National Liberation Committee" and a network of parish priests. But they had to sacrifice everything – their home, their possessions, the children's education and even their surname, which they had to change twice to bury their true identities. Due to the circumstances, Giuliana's values are strongly marked by the events of her childhood. With little interest in material possessions, to this day, solidarity, good human behaviour, and the worth of education are dear to the 84-year-old. While she only attended one and a half years of primary school, she always sought out independence and knowledge and managed to continue her education after the war, caught up with the lost time and graduated University in three subjects. Highly educated and with an open mind, today, Giuliana emphasises that books have saved her life, especially after her husband's passing away two years ago.

> "I love literature, this is the centre of my life. I became a widow a year and eight months ago, if I didn't have literature I would be lost, because due to my legs that really hurt, I lie down and read, read a lot. My house is full of books. It is what allows me to overcome this thing with my mind, you know."

The legacy of older adults resides not only in individual but also in collective memories (Halbwachs 1980) of a generation that grew up in post-war Europe marked by poverty and hunger and early experiences of loss and sacrifice. Comments such as "To this day I cannot throw away food" or "My generation saw a lot of death; one gets used to it" appeared frequently in our conversations. Furthermore, as demonstrated in Giuliana's case, with poverty and war also came a lack of opportunities for good education – a fact often recounted with disappointment – or free choice to follow one's vocation or interests, at least in the first instance. Yet, their life stories also show the importance of agency and how it is never too late to change one's fate. Thinking back to his childhood, Walter (80) from West Germany vividly remembers the bombing of Düsseldorf and how he had to flee and stay with his aunt on the border of Switzerland, separated from his parents. These circumstances meant that his school years were interrupted and cut short. With little prospects at first, he started a youth apprenticeship in a print and newspaper company at the age of 14. Despite the difficult start, he worked his way up with diligence and talent, attended adult education courses and managed to achieve a high position in which he invented a digital programme for advertisement placements that is used throughout Germany to this day. Proud of his work and how he managed to "become someone", he applies the experience that everything is possible whenever he gets stuck with a new digital gimmick and asserts that fear of failure should never keep one from trying, no matter one's age.

In their youth, some individuals had to struggle with the added challenge of bodily or mental disabilities. In her childhood, Vicky, a deafblind 64-year-old woman from a small village in Tenerife, Spain, suffered from intersectional discrimination as multiple "markers" of her social identity (disability, gender, and class) combined in overlapping modes of disempowerment (see also Crenshaw 1989). Despite her hearing impairment, at school "oralism" was imposed and she was not allowed to sign, and if

she did, was punished for it. Born in a hearing family with two male deaf siblings, Vicky also suffered from gender discrimination and, compared to her brothers never received higher education nor offered the same prospects. The structural failure to provide her with opportunities for learning had a lasting impact on Vicky's life. While she can communicate in basic Spanish sign language, her ability to express herself in it is limited and she has never had a paid job. Furthermore, the discrimination she experienced in her early years, both as a woman and as a differently abled person, meant that she remained financially dependent on family members and state pensions, hindering her opportunities and integration in society.

Despite these impositions, now, at the age of 64, Vicky has managed to carve out spaces of independence. The death of her mother to whose care Vicky devoted most of her adult years, forced her to rethink her life, move to her own home and start afresh. She approached FUNCASOR, the Canary Foundation for Deaf People, who helped her bridge communication limitations through guide interpreters and attend adult education courses, The inheritance she received brought some independence as Vicky now has sufficient resources to make her home accessible for herself through the installation of assistive technologies to overcome the limits of communication, receipt of information and independent living.

8.2.1 Lessons from the Past, Advice for the Future

Notwithstanding obstacles and scarcity, our participants often pointed with joy to the strong community support they felt "back then" and how people were 'happier" with the little they could afford. For example, Ligia (75) from Portugal remarks upon the camaraderie among common people in the past. According to her, the hardship of being stuck between the 'communists' on the one side and the fascists on the other created "a solidarity that doesn't exist today." Equally, Helena (79) who grew up and lived all her life in the Czech Republic mentions the importance of social networks, no matter the material circumstances:

> "My childhood was very nice, because in 1948 we moved to the street where I still live. (…) the apartment was very, I would say, uncomfortable, divided, but there were still such nice neighbourly relations, and we played on the street, there were no cars anywhere (…), in winter there was sledding, in summer there was a swimming pool (…) so it was actually an Eldorado for us children."

Additionally, in central and northern European countries, the post-war area introduced a period of hope and renewal marked by a *Zeitgeist* in which, with hard work, everything seemed possible. While different countries saw uneven political and economic developments, the establishment of welfare systems, improvements in medicine and workers' rights, women's empowerment, or improvements in the rights for people with disabilities took place throughout Europe. 79-year-old Gisela from Italy

reflects on these changes and how in comparison to societal achievements, recent material improvements have not enhanced people's quality of life in the same way:

> "It changed for the better for some things, but for other things I think it changed for the worse. (…) poverty was more prevalent when I was a child, even if it surely exists also now. However, I feel like we were happier than the young people nowadays, even the ones who are not poor, (…) I can say that we lived in poverty, (…) but there was more solidarity between people. People are so selfish now, that I am convinced that people who have problems now suffer more than before."

Looking back at his life, Achilleas, a 65-year-old man from Larissa in Greece shares the opinion that social cohesion and community thinking are more rewarding than personal gain. To this end, Achilleas, who has been a wheelchair user for the past 39 years, has worked tirelessly as a leader in his local government for improvements in public space, greater awareness training and, above all, confronting stigma associated with disabilities. Thinking about the collective, he has become sensitive to the needs of every person, with a disability or not. "I learned to help my fellow man in his problems. My disability was and continues to be a school that made me a better person."

Like the above examples, many older adults have highlighted the importance of confraternity, neighbourly relations, and solidarity. Reflecting on the future of the next generation, they express their concerns about what they see as an increased fragmentation of society. In an ever-expanding world they feel that their immediate surroundings are increasingly influenced by structures beyond their control and belonging, and create a growing need for mobility, which renders maintenance of community life and traditions difficult. 69-year-old Christos from Greece is a keen defender of heritage, national identity, and solidarity. He acknowledges the improvements brought by the European Union, but also mentions the loss of what he defines as traditional work, which forces people to leave the country. Reminiscing on the lack of stability in local living conditions he is sceptical of the future.

> "The young children, workers' children are gone abroad while Greece needs them. Are they going to come back here? I don't think so. I'm worried about that. Even my grandchildren will graduate, beyond that what happens, the doors are closed. They will force you to go abroad and no one will come back."

Offering a different view, Simon (70), a Czech national from the Roma minority, in turn shares his disappointment with the young generations, who in his view, care too little about collectively shared experiences, something he treasured in his childhood:

> "When I was younger, we used to organise festivals or summer cinemas to keep the neighbourhood alive. Nowadays, the youngsters all sit at home with their computers and large screens."

The decreasing face-to-face interactions introduced by the digital revolution or collective events that teaches social behaviour and integration is widespread amongst older adults speaking about the "future of young generations".

These worries have increased with the coronavirus pandemic. Ligia from Porto, who, as mentioned above, struggled through a dictatorial regime, describes governmental restrictions such as the prohibition of drinking a coffee in the bakery as "a farce" and then expresses her concerns about the future of society:

> "When the pandemic is over (…) society itself will change in many aspects. The need to work at home will create more mental problems for people, because whether we like it or not, face-to-face work is important. I mean banal things, noise of the phone ringing, a boss who calls and tells you to go to the office to get this or to get that... socialising... because, an office forces you to have contact with each other. Whereas if I'm at home, I'm there in silence without seeing anyone around me. I think that's horrible. I think mentally that will have a huge influence on people."

Conversations about the coronavirus pandemic furthermore brought about older adults' apprehensions for their children's financial wellbeing and the wider impact the crisis will have on society. Reminded in unexpected ways about shortages of former times, Hannelore (76) from Saxony told us: "The first months, when these hoarding purchases came in and then you went to the market and saw the empty shelves. It reminded me of the economy of scarcity in the German Democratic Republic (GDR). That depressed me. Not because I couldn't buy a pack of toilet paper, but because of the overall state of affairs, as if the past was somehow reaching out to me." Thinking about the future, she then adds in distress,

> "What will happen to the many people who are now worried about their livelihoods? What will happen to the entire economy? What will happen to the cohesion of society - since the resistance to the Corona measures is growing so much? That depresses me. The uncertainty really depresses me."

8.2.2 Adaptation, Nostalgia and Hope

Personal, societal, and cultural transformations are a part of life and the 20th Century has seen plenty of these. Having participated in past achievements, the misfortunes and fortunes of today's world, older adults emphasise that they are more than their present selves. At the same time, no matter their current contributions to society, they feel they should also be valued for the life's work – a claim not always fulfilled. Signe, aged 88, grew up in the post war era and lived 40 years in the former GDR. The mother of two is a pharmacist who worked all her life, sometimes up to 60 hours a week. Full of ambition and with the best education in mind, she completed not only her vocational training but later added a higher education degree to become an engineer in

pharmaceutical management. In her "old world" as she calls the GDR, Signe was very content. When it all broke apart, her education was no longer recognised, and the achievements of her generation were dismissed and disregarded.

> "That's what annoys me so much. In principle, all achievements of this founding generation are simply negated, simply deleted and destroyed. You don't have to be surprised if this stupidly continues to perpetuate in the younger generation."

Always a keen defender of higher education and hard work, Signe suffers to this day from the lack of acknowledgement of her merits. But even more so, she regrets that with the reunification of Germany, all GDR structures were dismantled without differentiation even though GDR's health and educational systems had useful lessons to offer (see also Chapter 7, Formal Care).

Speaking about the educational sector, Ludwig (69) equally feels that past achievements of the GDR are wrongfully dismissed. The current educational system, he argues, promotes a model that has been common during GDR times. but is now talked about as the Swedish standard: "you can't say that we should learn from the school system of the GDR and if you do, you're still one of 'the old ones'. But if I take the ideological element out of schooling in GDR times, let's say, we had a system that was very good." Countering historical negligence, Ludwig adds what few know in Central Europe, "The Swedes were in the GDR during the GDR era and adopted the GDR school system in Sweden. And that's why now, when they say we should adapt the Swedish model, then all East Germans know what is meant by that. But you just can't say it's from the GDR, you'd immediately be put into a box and you're just not up to date."

Hanna from Finland also argues for the importance of bringing together the best of past and future. Reflecting on the increased availability of new technological inventions and digitalised health care across Europe, she expressed her worries about isolation and a lack of direct contacts that might come with it. The 81-year-old appreciates the value of technological innovations but highlights the importance to retain human to human contact.

> "Well, yes, when it comes to the point, when an old person needs help, they start to become very tied to a place, you know. And I feel like I would want someone to come once a day to bring food, and for it to be a person, they would have time, and not like a robot just delivering, but like, uh (sigh), I'm certain that like these kinds of person-to-person contacts are far more superior to just using technology in the caring for the elderly, yeah."

To Hanna interpersonal relations are at the heart of wellbeing and the idea that "robots" who "do the job" would replace physical contacts in the future induces a fear of loneliness and generic help that loses sight of individual needs and personalities.

68-year-old Saverio from Italy also has found a way to transmit the value of past traditions while keeping up with technological developments. The father of two sons lives with his extended family in a village nearby Bologna. He is active in the social and cultural environment of this region and created an ethnohistorical museum that holds events to teach about tools, products, dialects, and traditions from his area. Sceptical of new technologies, Saverio nevertheless engages with social media and new means of communication to keep up with what in his view is "the inevitability of digitalisation". He explains change and the friction between past and future. "I guess almost all the people, day by day, get used to new situations. For example, we got used to safety belts and it seemed impossible before. The first few times, you felt trapped: now, if I don't wear it, I feel uncomfortable." Saverio applies this insight to his idea of a multimedia platform to host interactive stories of old people as part of his museum, so that they can remember their events, talk about them in creative ways and share them with the coming generations.

Old or young, people develop all kinds of strategies to cope with societal, economic, technological, and personal changes, including the coronavirus pandemic. And so, even if it is sometimes hard, Hannelore remains hopeful:

> "Humanity has already overcome quite different crises in the world. Perhaps people have a primal power somewhere to cope with difficulties. When I look at photos of Germany or other cities after the Second World War and compare them with pictures today, I think, 'People have a lot of strength and a lot of will to change things for the better.' (…) In a way, I believe that this will happen again. That is perhaps my source of strength."

8.3 The End of Life

Death, dying, inheritance and remembrance are topics that came up in all our conversations. Talking to our research participants they shared their heterogeneous philosophies about time and death, often expressing how they want to be remembered and the legacies they seek to leave behind. They talked about the process of setting up a will and arranging for their own death as well as sharing painful experiences of losing a partner and the coping mechanisms developed.

8.3.1 Time, Death, and Remembrance

Let us return to Donatella's story at the beginning of the chapter. As mentioned, memories are essential to Donatella and sharing her life lessons through her pictures on the tablet has become a valued part in her interactions with the grandchildren. Regularly, she pulls up the picture of her beloved husband and herself in the mountains, to show her 'naughty' granddaughter what a man's gaze looks like when he is the "right one", asking her "Is [your boyfriend] still looking at you as your grandfather was looking at your grandmother?" Passing on her wisdom on love and

relationships is an important part of her legacy. Aware of the importance of this picture, now stored on her digital device together with all the other memories of her long and fulfilled life, the interviewer suggested printing the photo to which Donatella responded in astonishment,

> "Why? I am going to be cremated, as my husband was (…) So I can't fill my coffin with all of these things, and there is no need for it anyhow."

For Donatella, material goods are of no importance. It is people and relationships that count together with the memories that she keeps in her heart and on the tablet and hopes for her children and grandchildren to remember.

Like Donatella, 83-year-old Heinrich from West Germany, wants to leave a legacy, which to him means spending time with loved ones and sharing his memories with his descendants. Often disappointed about the lack of interactions with his grandchildren, he found joy when they started to show interest in his life: "Now, my grandchildren want me to write down my memories from my childhood, the war, and how we lived then. I want to do it, but there is never time". Time is an important factor in ageing and like Heinrich, who is too busy to write his memoires, other interviewees have equally lamented the lack of time to follow their many interests and hobbies. Like Walter who put it this way, "I don't have time. When I was working, I didn't need a calendar. Now I need a calendar."

While some older adults feel that they are living against the clock, others, however, are not afraid of death. To them, waiting for the end of life is a natural and accepted aspect of life. Madalena, a 73-year-old woman from Aveiro, is puzzled about the wish to grow old and why 'they', as she says, want old people to live a long time. "I think people also have to have a time to die. Because there are things I do not want to see. I do not want to see the robots, I do not want to live in a society like this ... there is a time to live and a time to die." Similarly, the biologist Ludwig from Dresden, who presently enjoys life to the fullest, is not afraid nor worried about death: "I don't think much about it – it's a natural part of life". He even goes a step further to express his vision for humanity and the world as a whole and cynically reveals:

> "If man no longer exists, then the earth no longer has any problems. My wife is always angry with me when I say that man is working intensively to abolish himself and one can really only keep one's fingers crossed that this will happen as soon as possible."

Thinking about death and the planet's future, the biologist finds comfort in the natural cycle of life. To others a religious approach and belief in God brings peace, such as to Susanne, an 85-year-old widow from near Cologne, who told us "I think I won't be groping around here in the world for too long either. I'm 85 and that's an age at which you can say goodbye. I can still decide what I do while I'm here, but man thinks and God guides. So, when the time will come, none of us knows." Xenia's approach to

death as a never-ending cycle is equally albeit differently grounded in a belief in transcendence. Death, she recalls, has always been on her mind, even when she was a child. However, since she became a mother, she feels grounded, knowing that she has 'roots to the future'. Now, without fear or worries, she believes that even in death she will be around her children. And so, while in her opinion funerals are for the living and her children might as well "bury me in a carton", she is comforted by the hope that she will be reunited with her loved ones, living or dead, stating "My soul is with them, my body doesn't matter."

In our research, we saw a great many responses to the way older adults think about life, death, and the future beyond their physical presence in this world. Responses diverge on the significance of material possessions, religious beliefs, and remembrance, and more than once, older adults expressed their scepticism towards a prolongation of life by all available means. Furthermore, despite the diversity, most have attributed a high significance to interpersonal relations and great value is placed on intangibles such as memories as well as material matters. Passing on one's material possessions and leaving everything in order is therefore another significant ritual in the later life course.

8.3.2 Values, Possessions, and Inheritance

Pauline, an 84-year-old widow from Northern Ireland seems content with her life. The diligent woman loves to write her diary and reads two newspapers a day. When we asked about her future plans, however, she was hesitant and mentioned the loneliness she felt since her husband's death: "We did a lot of planning, but since my husband died, no, I don't make any plans for the future. I let my son make any plans he wants for me, so I have my funeral planned and a grave prepared. I have a will sorted out. I suppose that's my plans for the future is it?"

While Pauline's response came with a sarcastic wink, passing on material possessions and leaving everything in order is indeed important in later life. Ludwig, (69) from Saxony (see also opening vignette in Chapter 2, Social Worlds), has put a lot of time and effort into organising his will. Living in a reconstituted family with his wife, in addition to his legal documents, he has put together a supplementary folder documenting their insurance details as well as the codes and passwords of their digital accounts so that their descendants can handle their afterlives offline and online. Furthermore, they determined a legal guardian in case something should happen to them and reserved finances to pay for future potential care needs. As the couple had married late in life, burial grounds presented an additional problem. Not wanting to be separated in death, the couple decided against their respective family graves but for their ashes to be dispersed and scattered in a meadow, an emergent and increasingly popular form of disposal of human remains. (Prendergast, Hockey and Kellaher, 2006).

Ludwig believes in the importance of including the children into the preparation of his will to avoid family disputes in the next generation. Discussing inheritance with loved ones is however a task that can be difficult to do and sometimes brings disappointment as people come to realise how their values differ from succeeding generational cohorts. In Ludwig's case this disjuncture became visible when he wanted to allot items in his inheritance, but no one showed interest in what he regarded as one of his cherished possessions, the family's Meisner Porcelain.

> "It's a crazy change; we were happy to inherit porcelain, it's something special. Our kids however say A, that they don't have a display cabinet and B, they can't put that in the dishwasher, so they don't know what to do with it. That's a whole new way of thinking in the new generation, they have different values. That's striking, it really is a big cultural break – things that were still important to me, intrinsic values we had are no longer there. It's astonishing."

While Ludwig is saddened by the experience, he also admits, that it was "probably the same for his parents and we didn't even know it".

Some older adults who own private houses decide to legally pass ownership of their properties to their children during their lifetime. Cecilia, an 83-year-old woman from a rural area in Eastern Finland had that experience. Cecilia has three sons and five grandchildren and lives with her husband in a spacious flat in the city. In good Finnish tradition, the couple also owns a summer cabin in the rural areas, but slowed down by her husband's progressing Alzheimer's, they seldom go there anymore. With a heavy heart, Cecilia was about to sell the place when her middle son intervened with his wish to inherit the property. And so, after he came to an arrangement with his brothers, they 'gifted' it to him last summer. Glad to have put things in order, Cecilia however had a surprise coming, which she tells laughingly:

> "It was lovely when our eldest grandchild, the child of our middle son, asked me, 'Grandma, have you considered giving the cabin directly to me to avoid inheritance tax?'." Surprised and a little disturbed, she referred him to his father and in the meantime made sure that it was understood that included within the 'gift certificate' was a proprietary right ensuring that for the rest of her lifetime, "I can go there to have some rest whenever my husband is away."

Conversations about inheritance arrangements make us understand a number of practices and ideals. Ludwig's story highlights that writing one's will is usually a process rather than a fact and gives insight into the values and customs of different age cohorts, cultures and individuals'. Cecilia's story on the other hand reminds us about the importance for older people of retaining control over their lives and possessions and the joy some older adults find in sharing spaces and homes.

8.3.3 Loss and Bereavement

While the end of life is inevitable, Donatella does not regret anything, nor does she fear death. In a sad voice, however, she explains the pain she feels about losing her partner, "I just feel sorry because I was the one who was left alone instead of him. But it was not possible the other way round, so I'm adapting and waiting." For many older adults the loss of a spouse or child introduces a process of mourning and adaptation, rebuilding one's lifeworld in a new manner. The experience of bereavement sets into motion a process of grieving, and the need to restructure one's daily life and routines to adapt to the new circumstances and rebuild meaningful routines.

Franz, a 78-year-old father of two has recently experienced loss. His wife was diagnosed with cancer in June 2019, and, after a rapid decline, she passed away in July 2020, during the height of the coronavirus pandemic. Speaking only eight weeks after her passing, Franz remembered the situation vividly.

> "It was a catastrophic situation. Above all, the months of this year 2000 were an absolute horror. I had looked after my wife here in the house, cared for her, in as far as I could all on my own, and then I got help. But it was an experience I do not wish on anyone. It completely wrecked me. Thank goodness I'm healthy and well and I was able to handle it all."

In his life, Franz earned good money and lives in a huge modern bungalow style house, which originally belonged to his wife's parents but has been expanded to fit the family of seven. Now, with everyone gone, the house is too big and everything in it reminds him of his wife and past days. With many hobbies, boredom is not his problem, but as he explains, "sometimes your thoughts wander off to places you don't want to be." Especially walking the long corridor, where family pictures line the walls, remind him of happier times. When Franz had to care for his wife, he gave up his hobby of hunting and since her death, even though time now permits, he doesn't feel like returning to it. "I have much more time again, now that my wife is well taken care of", he tells me while his voice indicates his pain. And while Franz often feels lonely and sometimes "suffers like an animal in a cage", as he puts it, he doesn't want many people to come by and visit him. "I'm not a nursing case!" he points out vehemently, reclaiming his agency.

As people grow older, experiences of loss and bereavement happen more regularly. With that, changes in daily life patterns take place, often after 50 or more years of sharing one's everyday existence with a partner. Sadness and pain can be overwhelming, and loneliness, dislocation or depression regularly accompanies these moments of transition. Despite individual strength, family networks, neighbours and friends, support groups for relatives of the diseased and other social rituals ease the process and help those having to cope with loss. For example, 80-year-old Evelin honours her dead with daily visits to the cemeteries. To comfort her soul, she made it

her routine to walk from her home to the cemetery where her parents and brother are buried. From there, "I walk to the other cemetery, just opposite, where my husband lies and where I will join him some day". Since the death of her partner five years ago, Evelin moved to assisted living accommodation run by the protestant church in the centre of town, where she feels safe and cherishes the freedom to find everything in walking distance. Happy to have company of others on a daily basis, but still not considering herself 'old', she explains how the new environment enables her to support the 'elderly' by reading to them or taking a walk with someone, who 'feels a bit lonely' (for more, see Chapter 7, Formal Care Worlds). Since she lost her partner, Evelin attends bimonthly peer group meetings of bereaved relatives, an activity paid for by her health insurance. The mourning group to her provides a space for sharing her worries and, as she says, helped her through the difficult process of transitions.

> "So, there are those where a partner has died, a child has died. A self-help group, let's say, and that's always nice to know that someone else has exactly the same problems and worries as I do. That's good."

Support groups for sharing sorrow help not only to cope with the situation but also to find new companions or simply a "wee hug" which, as Alison from Northern Ireland points out, is sometimes all you need:

> "When my mum died my daddy talked about it and I find that's the best way. When something happens to a person, all you can do is give them a wee hug and say you are sorry to hear what happened. They only need to know that somebody is thinking of them that's all you need."

8.4 Conclusions

Older adults are more than their present selves. They have worked all their lives, have formed families, brought up children, travelled, walked streets in protest, survived wars and illnesses, and dealt with loss and renewal. As people grow older and life-stories lengthen, looking at who they have been, what they have done and what is recalled fondly or otherwise, represents a way to give significance to their present and keeps memories "alive" even when those who co-created them are long gone.

This chapter looked at two broad topics. In part one we discussed older adults' legacies – their memories, agency, and advice for future generations. We learnt that older people are more than their present selves and the importance of recognising their achievements and contributions to society (now and in the past). We highlight the importance of control, autonomy, and participation in all phases of life. Through insights into childhood joys and obstacles, we learnt that material improvements and new technologies are only one side of the coin and values such as solidarities, frugality and a sense of community are equally key to happy lives for many older adults. A discussion on overcoming scarcity in the past, or limitations in education and

discrimination, provided insights into agency and showed that it's never too late to follow one's ambitions. Finally, we engaged with lessons learned from societal transformations and listened to their advice to institutions and the younger generations.

Part two explored the end of life, death, inheritance arrangements and the experience of bereavement. We look at how people wish to be remembered and how they wish to leave a legacy in the – for many reasons – limited time they have. We then looked at ways older adults arrange their inheritance balancing the needs of their descendants and their own wellbeing. Finally, we attended to the experience of the loss of a partner and the processes that help them through the transformations introduced by the bereavement of a life partner.

Whilst some of our participants were critical at times of both their own and younger generations, the study of older adults' life-histories and legacies provides important insight and perspective into how individuals, families, communities, and cultures deal with transformation, crisis, and change. To conclude, we would like to reiterate the optimistic words of Hannelore as she shares her views on the future.

> "People have a lot of strength and a lot of will to change things for the better'. (…) In a way, I believe that this will happen again."

8.4.1 Insights and Reflections

Considerations for policymakers, solution developers, and service providers:

- There is a tendency to see older adults in a snapshot as "old" whereas they experience this moment as another scene in an ongoing production. In other words, people are more than their present selves. How can the rich contextual experience of an individual's life be respected, and family members be assisted in remembering it?

- In this chapter we observe the hasty dismissal of past achievements and structures that is often experienced as diminishing. Solutions developed for older people need to address such blind spots. How might the perspectives and dogmas of today, hide or dismiss effective solutions from the past?

- How might services better integrate with the rituals and processes of restructuring one's life after the death of a family member? Are there opportunities to facilitate processes of transition and the interpersonal creation of legacies?

CONCLUSIONS: AGE, AGENCY, AND A SUMMARY
Chapter 9

Chapter keywords: Identity, Old Age, Ageism, Participation

9 CONCLUSIONS: AGE, AGENCY, AND A SUMMARY

In this report, we have provided a window on to the lifeworlds of people in several settings across Europe, while providing some tools to frame how real people in real situations experience a sense of control or alienation, hope and anxieties, well-being and infirmities as they come to term with a very complex moment in the life cycle. The main point that we have tried to convey is how humans experience various aspects of their lifeworlds as interconnected, and that experiences that tend to undo those connections are experienced as problematic.

Covid was one such experience for many of our informants. When asked about "age" in an interview conducted in autumn 2020, right at the beginning of the third coronavirus wave in Portugal, 73-year-old Madalena said:

> "I got older, that's what I tell you. I've aged twice as much, because of the pandemic. They stole a year from me, instead of 73, I'm already 74 and a half. I'm already one and a half years older, to almost 80 in a little while."

Madalena's perception of her age changed with the coronavirus pandemic and demonstrates one of our central points: age is less a number than a social perception and way of thinking about oneself in relation to one's surroundings, constraints, life choices, health, connections, body, and being. To highlight the ways in which some of our research participants subvert stereotypes of ageing – symbolically "wearing purple", as Jenny Joseph has suggested in her poem "Warning" in the 1960s (Joseph 1961) – we will end this report with a discussion on age, ageing, and older adults' agency, before summarising some key conclusions.

9.1 Perceptions of Ageing and Ageism

From a societal perspective, age provides a number that determines certain life course boundaries such as retirement from paid employment, or access to public pensions, a travel pass or other senior citizens reductions. Whether or not, an older adult identifies as old, however, is largely dependent on how they live, the ways in which others treat them, and how the challenges, limitations and opportunities of the later life course are received. Being asked to point what is important at the later stages of life, Eleftheria who opens Chapter 6 (Informal Care Worlds), responds without hesitating:

> "Health, my girl, health. Health and love. We had health in our youth, then we got married and since then we were healthy. So was my husband, he was healthy, he worked and we loved each other. Now we are not healthy, but we still love each other."

Feeling healthy and without pain is a key aspect for happiness and was often mentioned as the key differentiation in self-identifications of young and old. Eleftheria highlighted this point saying, "Sometimes I feel like a young girl. But if I am in pain, my leg for example, I feel old. But in general, I do not feel [that] I am old." Similarly, Jamaican-British 83-year-old Nigel from Northern Ireland mentions that while his body might fail him, he hasn't grown old mentally, "I don't feel old, just that I am more limited now, with aches and pains and different things that happen. But I still want to do everything I used to do when I was young. Just the same." Doris from Finland also shares the feeling that health is a core aspect of feeling "young". "When my friends turned 40, they were horrified, and even more horrified when they turned 50. Sometimes it occurs me that, dear lord, I'm already 60, I'm already 70. But age has never meant much to me, I have been so healthy."

Even though the nominal category of older adults has diversified, older individuals often still experience segregation and exclusion simply because of their perceived age. Such age-related discriminations can be subtle and range from the way people talk about or to them to structural restrictions, exclusions, and contempt. As Joke de Ruiter-Zwanikken, representative of the AGE Platform Europe, pointed out in the October 2021 SHAPES dialogue workshop, seemingly harmless questions that begin with "do you still…" assume a focus on deterioration and increased inability to continue one's way of living on the basis of age alone rather than thinking about the 'whole person', their interests, history, abilities and hobbies. Language used in hospital environments and elder care reflects similar tendencies. Charlotte, whom we met in various chapters of this report, has worked for years in hospitals as a mediator and patient advocate. In her opinion, all too often, patients are labelled already upon entry and older adults are described in a derogatory way that indicates a lack of respect for the older individual "For example when they say this is 'a sweet granny', it makes me feel sick."

While anthropology and other social sciences are comfortable in deconstructing categories like gender, race, or ethnicity, "age" is still too-often framed as natural, biological, and theoretically inert; yet is clearly a space of cultural expectations and contestations and being old numerically does not equal social age or feeling "old". To the contrary, to some of our research participants, age is more related to appearance, social activities, and the places they go to. 73-year-old Kalliope from Greece told us, "Women my age, for instance my friends, look exactly the way I do." Kalliope's appearance is not what many might expect of women her age. Her outfit is modern, she has short hair, and she usually goes out on her motorbike, which she has been driving since she was a little girl. To explain how in her view older people of her acquaintance age differently nowadays compared to the past, she adds,

> "They take care of themselves, looking nice and beautiful, when they go out for a coffee etc. Sometimes, people might criticise the places I am going out. They

believe that they are for younger people, but I have no issue with that. I am still young. I am still going to places, where young people hang out."

The concept of maintaining connections across generations and one's social standing and appearance came up often in conversations about identity, personal interests and preferences, and perceived ageism. The importance of style and appearance also connects to the potential fear of prejudices associated with old age. It sometimes even hinders older adults to accept what they believe to be 'stigmatising' digital and physical devices that might situate them into the category of "old" they themselves don't feel comfortable with. It is thus imperative for designers to take into account not only functionality but also the style and visuality of tools. In Northern Ireland, for example, women in past generations were expected to wear an apron as a core defining dress of a "granny", whereas now it's "hard to tell" when someone is an older woman, 82-year-old Alison tells us.

> "[These days], grannies dress young, some grannies dress ridiculous, but my granny wore black and a flowery apron and that was her, the grannies now some are fantastic looking, well nowadays some grannies are having kids even. I think, it is very hard to pick who is a granny [nowadays]".

Detailed narratives of our research participants' perceptions of their parents and grandparents' experience of ageing, counterbalanced with their assessment of their own generation, suggest there has been a tremendous shift in recent decades of what it means to "grow older". For example, Xenia (66) eloquently describes how in her view due to prolonged life expectancy and changing demographics around ageing there is a new cohort of older adults that didn't exist in the past. This, in her opinion, created a need and an obligation for older adults to participate in societal affairs beyond (early) retirement.

> "We have at least a period of 10 to 15 years in which I'm not old and frail, even if I can't walk right now or something. But my head is clear and I can work, I could do activities. And I'm not alone, it's a mass of people, it's not like it used to be, that it's a pyramid, but we have a big, fat belly, and there are all the teachers who are retiring early at 56, they're all stuck in there. What are they supposed to do? We also want to do something for society. So that's a period of time that didn't exist in the past, when my parents retired, they didn't do anything anymore."

Noting that the music of her generation was the music of the Rolling Stones, most of whom are still gigging, she furthermore adds that participation should be something driven by the older population not given to them.

> "The older generation must help shape society. We must also demand this […]. That is very important. We have to participate, it's not about something we are

kindly entitled to, but we also want to do the right thing for younger people. Our experience is useful, it is important. Yes, I can get excited about that!"

Throughout this report, our research participants have mentioned the importance of agency, participation, and their wish to contribute to all aspects of social and cultural life. In building the SHAPES ecosystem based on the qualitative, in-depth insights from this report and the T2.1 database as well as the use cases developed from this research is a significant step towards this direction and responds directly and in a respectful way to the needs, hopes, and suggestions of older adults.

9.2 Summary

This report built on primary ethnographic data with 94 individuals in Czechia, Finland, Germany (2), Greece, Italy, Northern Ireland, Portugal (2) and Spain resulting in 378 hours of recorded, transcribed, and translated interview time. This rich database of the lifeworlds of older adults covers nine core themes that we addressed with each research participant. In the subsequent analysis of the data for patterns of experiences, challenges, and needs, responses emerged that led to key insights presented in the seven chapters of this report. Empirical findings on participants' ways of life and interpretations of living, their use, acceptance of or challenges with technologies and services, as well as the current rupture of familiar sociality during the COVID-19 pandemic, demonstrate the importance of a holistic interpretation of processes, practices, participation, and purpose in the later stages of life – the 4 Ps we chose as core concepts underlying the interpretation of our findings. Furthermore, as this conclusion showed, conversations with older adults and a complex analysis of their lifeworlds disrupt expectations and boundaries associated with "the old" that all too often are used as the drivers for innovations.

The core finding that runs across all chapters of the report is thus an awareness for meaningful entanglements between all associated facets of people's lifeworlds. We identified that a full comprehension of older adults' self-identification, their needs and potential solutions can only develop from an intertwined reading of the connections between physical and emotional requirements, unexpected barriers to social participation and independence, the meaning and interpretation of home, community, and services, as well as their own capabilities (Nussbaum 2013) to participate in decision-making and creative solutions. It is essential for solution developers, designers, and service providers to approach older adults' needs and challenges with respect for their agency, participation, and control over decisions which impact on them.

The substantive content of this report was structured into seven chapters covering core topics relevant to the SHAPES pilots and the consortium as a whole.

In Chapter 2 (Social Worlds – Living, Learning & Liasing) we addressed a) how older adults' lives look like when seen through their relationships and activities and b) how they learn, their use of technologies, and the barriers and frictions they confront. The chapter demonstrates how acting in the lifeworld involves processes of constantly adapting to changing contexts and new circumstances and that the practices of doing so depend largely on an associated feeling of purpose and the motivation they have to participate in activities, social networks and digital media.

Chapter 3 (Moving through the World) discussed mobility, access, the meaning of home and community environments. It analysed physical and bodily challenges, the use of technologies and creative strategies older adults develop to negotiate and maintain a life of choice, independence and quality. In the second part of the chapter, we engaged with the limits and constraints of moving around at home and in public environments and how fear of falls, disabilities and other health issues affect their perceptions of ability, choice, and participation.

Chapter 4 (Working Worlds) attended to three domains of work and labour involved in the later life course, namely managing domestic life, contributions to civil society through volunteering and active participation, and paid labour. The chapter highlighted how people's daily tasks differ depending on their living circumstances and localities and how, contrary to the assumption of senior citizens as in need of support, older adults participate in manifold and meaningful ways to societal processes, giving them in turn financial compensation, appreciation, and recognition, as well as purpose and meaning.

In Chapter 5 (Financial Worlds – Spending & Affording) demonstrated the challenges of maintaining financial wellbeing in the later stages of life, especially for widows reliant on their late partner's pension and facing increased risk of losing self-sufficiency. Furthermore, we highlighted the ways in which older adults support their offspring and the importance for developers and policymakers to take into account the restrictions and difficult choices people have to make to cover daily expenses in old age.

Chapter 6 (Informal Care – Providing Care) explored care giving practices of older adults. Countering the burden discourse, we highlighted how senior citizens participate in and facilitate care practices in the family and society and how their contributions are key to maintaining care structures in Europe. Furthermore, we attended to their experiences of and recommendations for useful technological support and how certain improvements in support systems would help against challenges in these practices in home settings and enable self-care and integration.

Chapter 7 (Formal Care – Receiving Care) explored the experiences of older adults accessing and navigating formal care through hospitals, GP practices, and nursing homes. Gaps in service and issues of communication, agency, trust, and empowerment are central to our analysis with many older adults resistant to contexts

where they risk being objectified as a "problem to be managed" rather than a person to be engaged.

Chapter 8 (Legacies and the Future) focuses on the entire lifecycle and engages with the past, present, and future of older adults' lifeworlds. Specifically, we explored the way people wish to be remembered, the recommendations for, and critiques about, new generations, and the importance of building a future on lessons from the past. In the second part, we looked at thoughts about and arrangements for the end of life, the meaning of loss and bereavement and discussed how older adults deal with transformation, crisis, and change.

As the chapters of this report demonstrated, contributing to society and discovering oneself is a never-ending process and every day brings new adventures and possibilities. Living, loving, and learning need not stop, regardless of age, especially if sensitively designed and sufficiently resourced supports are in place, such as family, friends, communities, technologies, and services, during times of change. The later stages of the life course are seldom experienced without emergent and recurrent health issues, changes in routines and everyday practices, and an increased need for support of different types (by family, peers, or institutional services), but they also carry many unexpected creative and fulfilling opportunities resulting in a sense of personal and social flowering, rather than a long, slow withering of the self. 83-year-old Polly from Northern Ireland explained she has lived much of her life according to other people's rules, tastes, decisions, and dreams. Until the age of 73 she felt controlled and underestimated in the workplace, by unions, local council, her ex-husband, her neighbours, sister and her nephew and nieces. It is only at an advancing age, that she started to feel the confidence to make her own decisions and to stand up for herself and the community (see Chapter 2, Moving through the World, for details). This process of liberation, of feeling her newly found strength highlights the possibilities of acting against injustice (practice), personal growth (process), societal contribution (participation), and empowerment (purpose) no matter one's age. To end this report, we therefore want to give the last words to Polly.

> "See I have never been allowed to make a decision, any decision. So I hadn't the confidence to make my decision. When [someone] asked me what I would like, I answered by asking them what they would like. I couldn't… Maybe I felt guilty about having what I wanted?
>
> Then, [ten years ago], I met a friend who said I had good tastes and I was nice, and I began to like myself. It sort of was like a journey, I needed to sort 'myself' out. Sometimes I wonder if those who decide for you realise what they are doing? I can't figure that out but that's no longer my problem."

10 ETHICAL REQUIREMENTS CHECK

T2.1 data used in this report consists of a core of 94 Case studies from 10 SHAPES pilot and reference sites and from our WFDB colleagues working with the deafblind. The data is composed of extended ethnographic interview transcripts (with supplementary field notes and visual images as appropriate) as covered in our consent procedures. The Task Research Plan went through the Social Science Ethics Committee at Maynooth University (SRESC-2021-2428941). All interview participants have given their informed consent to participate in this research after reading the information sheet handed to them (see Annex 2) and were provided with the opportunity to ask questions regarding the work and the use of their narratives prior to and throughout the interviewing process. All transcripts (anonymised, in original and translated into English), field notes and images, have been put into the qualitative data research programme NVivo, to which for privacy reasons and as consented to by the research participants only members of the T2.1 NUIM team have access. The resulting database was used as a pathway to the analysis of the interviews that is presented in this Final Report (Deliverable 2.1) and other dissemination activities in SHAPES (see Introduction).

Ethical issue (corresponding number of D8.4 subsection in parenthesis)	How we have taken this into account in this deliverable if relevant)
Fundamental Rights (3.1)	Research process and consenting actions fulfilled the set requirements in D8.4.
Biomedical Ethics and Ethics of Care (3.2)	N/A
CRPD and supported decision-making (3.3)	Research process fulfilled the set accessibility requirements in D8.4 for differently abled participants, including professionally contracted interpreters and communication mediators.
Capabilities approach (3.4)	Research and analysis actions fulfilled the set requirements in D8.4.
Sustainable Development and CSR (4.1)	Research and presentation of findings fulfilled the set requirements in D8.4.
Customer logic approach (4.2)	N/A
Artificial intelligence (4.3)	N/A
Digital transformation (4.4)	N/A
Privacy and data protection (5)	Research process and consenting actions fulfilled the set requirements in D8.4.

Cyber security and resilience (6)	N/A
Digital inclusion (7.1)	N/A
The moral division of labor (7.2)	Research process fulfilled the set requirements in D8.4.
Care givers and welfare technology (7.3)	N/A
Movement of caregivers across Europe (7.4)	N/A

Comments: _____

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Annex 1: Participant Index

Participant	Gender	Site	Age	Sections
Achilleas	m	Greece	65	3.3 // 8.2.1
Adelaide	f	Aveiro (PRT)	75	
Aikaterini	f	Greece	83	
Alberto	m	Porto (PRT)	71	7 (opening vignette) // 6.4 // 7.1 // 7.2 // 7.3
Alegría	f	Spain	72	3.3
Alfredo	m	Spain	69	
Aliina	f	Finland	66	
Alison	f	GB-NIR	82	5.4 // 6.2.1 // 8.3.3
Ana	f	Aveiro (PRT)	73	
Artur	m	Aveiro (PRT)	73	2.4.1
Athanasios	m	Greece	74	
Barbara	f	Czechia	63	7.3
Beatriz	f	Aveiro (PRT)	72	
Bernardo	m	Aveiro (PRT)	74	4.3
Bert	m	GB-NIR	70	2.2.1 // 3.2 // 3.3 // 7.3
Bertil	m	Finland	78	5.3
Beth	f	GB-NIR	93	4.4 // 7.5
Cecilia	f	Finland	83	6.2.1 // 8.3.2
Charlotte	f	ObK (DE)	67	2.2 // 6.3 // 7.3 // 9.1
Christos	m	Greece	69	4.2 // 7.3 // 8.2.1
Danae	f	Greece	69	7 (opening vignette) // 2.2.1 // 3.2 // 5.5 // 7.1
Daniele	m	Italy	66	4.2
Donatella	f	Italy	92	8 (opening vignette) // 7.4 // 8.1 // 8.3.1 // 8.3.3
Doris	f	Finland	76	9.1
Eeva	f	Finland	70	
Eleftheria	f	Greece	75	6 (opening vignette) // 6.1 // 6.2.1 // 6.4 // 9.1
Evelin	f	ObK (DE)	80	3.2 // 5.2 // 7.4 // 8.3.3
Fanny	f	Finland	76	
Felipe	m	Spain	74	2.4
Francesco	m	Italy	73	
Franz	m	ObK (DE)	78	2.4 // 2.5 // 8.3.3
Frau Blume	f	Dresden (DE)	80	2.2 // 3.2
Gabriela	f	Finland	77	

Gertraud	f	ObK (DE)	92	
Gisella	f	Italy	79	3.2 // 4.2
Giuliana	f	Italy	84	2.4.1 // 3.3 // 8.2
Hanna	f	Finland	81	2.21 / 8.2.2
Hannelore	f	Dresden (DE)	76	2.2 // 2.3 // 3.3 // 5.3 // 7.3 // 7.4 // 8.2.1 // 8.2.2 / 8.4
Heinrich	m	Dresden (DE)	83	7.3 // 8.3.1
Helena	f	Czechia	79	3.3 // 8.2.1
Hugo	m	Aveiro (PRT)	77	4 (opening vignette) // 4.1 // 4.4 // 4.5
Iisak	m	Finland	65	
Isabel	f	Aveiro (PRT)	70	2.4.1
Ivo	m	Porto (PRT)	81	4.2
Jacob	m	Finland	76	
Jakub	m	Czechia	62	4.4
Jana	f	Czechia	73	2.2
Jiří	m	Czechia	69	4.4
Julie	f	Czechia	87	3.2 // 3.3
Jutta	f	Dresden (DE)	70	6.2
Kalliope	f	Greece	73	2.2 // 2.4.1 // 9.1
Laura	f	Dresden (DE)	69	4.3 // 6.5
Leonor	f	Porto (PRT)	66	2.2 // 6.2 // 6.2.1
Ligia	f	Porto (PRT)	75	2.4.1 // 8.2.1
Lorena	f	Italy	86	4.2
Lucinda	f	Aveiro (PRT)	72	4.4
Ludwig	m	Dresden (DE)	69	2 (opening vignette) // 2.1 // 2.2 // 2.4.1 // 2.5 // 4.3 // 8.2.2 // 8.3.1 // 8.3.2
Luis	m	Porto (PRT)	70	
Madalena	f	Aveiro (PRT)	73	4.4 // 7.3 // 7.4 // 8.3.1 // 9
Madge	f	GB-NIR	82	8.2
Manuel	m	Aveiro (PRT)	73	
Margaret	f	GB-NIR	76	2.3.1 // 4.4 // 5.1
Matilda	f	Italy	90	
Max	m	Dresden (DE)	70	4.3 // 4.4 // 6.5
Mike	m	Dresden (DE)	77	2.3 // 3.2 // 3.3 // 4.3
Miral	f	Greece	60	
Momi	m	Italy	75	2.3
Monica	f	GB-NIR	78	3 (opening vignette), 2.2 // 2.4 // 2.5 // 3.1 // 3.3 // 7.3

Monika	f	Czechia	82	4.3 // 7.3
Natalia	f	Czechia	78	2.4.1 // 5.5
Nigel	m	GB-NIR	83	2.3 // 4.3 // 9.1
Nikolas	m	Greece	84	3.3 // 4.2 // 7.4
Olga	f	Porto (PRT)	74	4.4
Patrizia	f	Italy	65	7.3
Paul	m	ObK (DE)	82	2.2.1
Pauline	f	GB-NIR	84	8.3.2
Penelope	f	Greece	73	4.2
Polly	f	GB-NIR	83	2.2 // 3.2 // 3.3 / 4.3 // 4.4 // 9.2
Rauke	f	ObK (DE)	88	
Robert	m	Dresden (DE)	77	2.3.1 // 2.5 // 4.2 // 4.4
Rosa	f	Porto (PRT)	75	2.2 // 2.3.1 // 5.3 // 6.5 // 7.4
Sandro	m	Italy	87	2.3.1
Saverio	m	Italy	68	8.2.2
Signe	f	Dresden (DE)	80	6.4 // 6.6 // 7.3 // 8.2.2
Silvia	f	Porto (PRT)	69	
Simon	m	Czechia	70	8.2.1
Susanne	f	ObK (DE)	85	5 (opening vignette) // 5.1 // 5.2 // 5.4 // 5.5 // 7.6 // 8.3.1
Ted	m	GB-NIR	71	2.2.1 // 2.4.1 // 2.5
Tomáš	m	Czechia	72	
Uwe	m	ObK (DE)	76	
Vasileios	m	Greece	79	
Vicky	f	Spain	64	8.2
Walter	m	ObK (DE)	80	2.4 // 4.3 // 8.2 // 8.3.1
Xenia	f	ObK (DE)	66	2.3 // 2.4 // 3.2 // 4.3 // 7.4 // 8.3.1 // 9.1

Annex 2

Information Sheet handed to all research participants (English version). For an audio accessible version of the Information sheet please click this link.

Maynooth University
National University
of Ireland Maynooth

SHAPES

INFORMATION SHEET FOR RESEARCH PARTICIPANTS

Purpose of this Study
The study, "Understanding Older People: Lives, Communities and Contexts", is interested in older people's lives, as part of developing a technology and data platform that will support healthy and independent living of older individuals. It focuses on the everyday lives of older individuals across Europe, their interaction with family, neighbours, friends, and social institutions (e.g. churches, libraries, swimming pools, football clubs) as well as their access to care institutions and health providers.

What will the study involve?
The study involves 2-5 interviews and interactions, using secure online technologies such as Microsoft Teams or WhatsApp, or the telephone. With the easing of Covid-19 restrictions and if this will be your preference, we also offer face-to-face meetings to complement or supplement remote online interviewing where governmental regulations on social distancing declare it safe practice to meet in person. We will discuss the aspects of your life and your community that are of interest to you. These topics can include, but are not limited to, your life-history, your community, your everyday life, your housing situation, and aspects of health, well-being and care. We will record our interviews and may ask you to share some pictures with us. We will also take notes of our conversations.

Who has approved this study? This study has been reviewed and received ethical approval from the Maynooth University Research Ethics committee and is guided by the main principle of ethnographic research *Do no harm!* ("Principles of ethnographic research" by the American Anthropological Association).

Will your participation in the study be kept confidential?
Yes, we will keep confidential all personal information that we collect about you during the course of the research. Your name or the names of any other person we will talk about will be anonymised through the use of pseudonyms in the transcripts of our interviews. Visual material will only be used for research purposes unless you agree specifically to the use of particular images for publication purposes. We will make the transcripts of our conversations available to you.

Statement on the limits of confidentiality: 'It must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority.

In such circumstances the University will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent.'

What will happen to the information which you give?
We will record our interviews and take notes of the environment, technologies and activities that you tell us about. We may refer to these notes during our next conversations to ensure that our interpretations of what we see are accurate.

We will keep recordings, notes and images on a password-protected computer that can only be accessed by the researchers on this project. Anonymised findings may be used in further research and/or dissemination activities.

Participation and withdrawal
Your participation in this research is completely voluntary and you may withdraw at any time by informing any one of us that you no longer wish to participate. No questions will be asked about your reasons. If you decide to withdraw your participation or not to take part in the research, there will be no negative consequences for you. It will not affect your relationships with any health or care institutions in your area. If you have any questions or concerns about the activity, please do not hesitate to turn to the contact person indicated below.

If you agree to participate in this research, we will ask you to provide your oral or written consent during our first recorded interview in which we will go through each point of the consent form. We shall read the consent form to you, ahead of our interviews, and keep it for our records.

What will happen to the results?
We will write up the findings of this research and present them as a report to the wider SHAPES consortium and to the EU Horizon 2020 funding body. Furthermore we will present our insights at National and International conferences and in various academic publications. We will make a copy of the research findings available to you.

What are the possible advantages and disadvantages of taking part?
We do not foresee any risks to your health, physical or psychological wellbeing arising from your participation in this research. The research, however, will help improve our understanding of the day-to-day lives of older people across Europe to improve their quality of life, community-based health and care systems and to increase the usefulness of digital and technological supports based on the insights you provide us.

What if there is a problem? At the end of each conversation, we will ask you about the experience and how you feel. You can contact me or my colleagues at any moment with any other queries and we will answer them to the best of our knowledge. [Insert site-specific support resources]

If you seek further information or if you would like to add to our interviews or change any part of it, you can always contact us.

Contact Persons

Dr. Katja Seidel   katja.seidel@mu.ie   phone: +436601280878

Prof. David Prendergast   david.prendergast@mu.ie
Prof. Jamie Saris   ajamie.saris@mu.ie

Thank you for taking the time to read this!

Annex 3

Some of the insights presented in this report and further research done in task2.1 are also presented as short vignettes in #SHAPESStories, a continuously growing section on the SHAPES website dedicated to the exploration of personal, social, and technological needs of older adults and their families.

To access #ShapesStories please follow the link.