



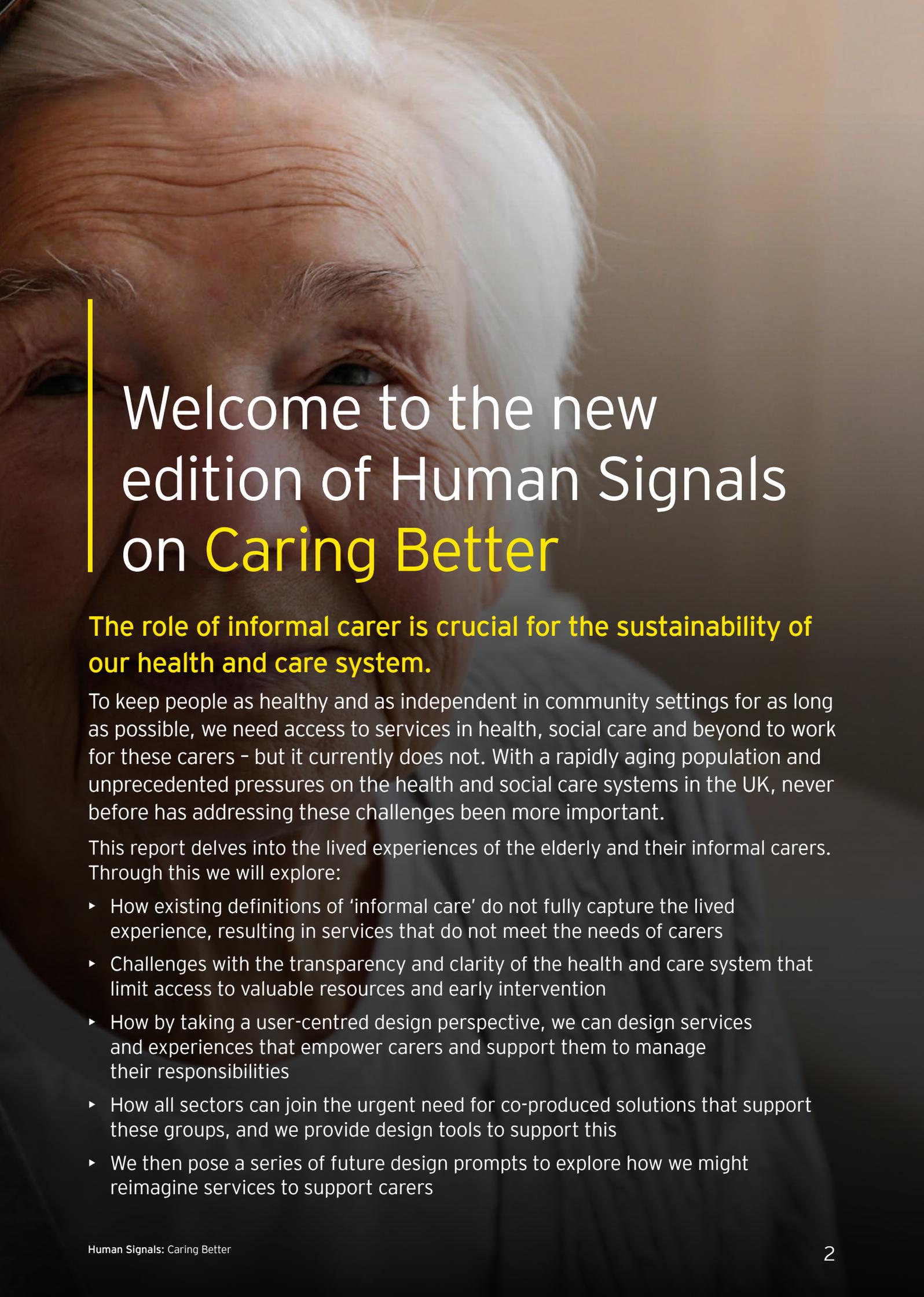
# Human Signals

Caring Better

March 2024



Building a better  
working world



# Welcome to the new edition of Human Signals on **Caring Better**

**The role of informal carer is crucial for the sustainability of our health and care system.**

To keep people as healthy and as independent in community settings for as long as possible, we need access to services in health, social care and beyond to work for these carers - but it currently does not. With a rapidly aging population and unprecedented pressures on the health and social care systems in the UK, never before has addressing these challenges been more important.

This report delves into the lived experiences of the elderly and their informal carers. Through this we will explore:

- ▶ How existing definitions of 'informal care' do not fully capture the lived experience, resulting in services that do not meet the needs of carers
- ▶ Challenges with the transparency and clarity of the health and care system that limit access to valuable resources and early intervention
- ▶ How by taking a user-centred design perspective, we can design services and experiences that empower carers and support them to manage their responsibilities
- ▶ How all sectors can join the urgent need for co-produced solutions that support these groups, and we provide design tools to support this
- ▶ We then pose a series of future design prompts to explore how we might reimagine services to support carers

# Human Signals: Powering transformation with insights and empathy

EY Seren helps organisations achieve growth by serving the needs of people, communities, and the planet.

Human Signals is EY Seren's proprietary thought leadership series, which focuses on the key issues and trends shaping our society from a human-centred research and service design perspective.



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## Foreword: **Caring better for communities**

Human Signals takes a human-centred lens to some of the biggest challenges we face in society today in order to uncover new opportunities to help brands in highly regulated sectors like healthcare, government, energy, and financial services help their customers make better choices and decisions, and get access to the services they need for themselves, their families, and the people they care about most in their lives. In this issue, we explore informal carers, the people they care for, and the challenges they face navigating services across the informal networks of care they create.

Today, 1 in 6 people in the UK over 80 have been diagnosed with dementia, and roughly 1 in 4 people in the UK will have a connection, and varying levels of responsibility, to someone requiring care. In the work we do in the sector and in the research we conducted for this Human Signals report, we saw real challenges across the healthcare sector, and adjacent regulated sectors, like banking, where the customer experience has been digitised over time to improve transactional efficiency, but doesn't often take into account a customer who may have dementia, supported by a family member who needs to have greater access and control of their bank account to manage day to day finances and protect them from fraud. Service failures inevitably create frustration for the customer and their support network, and additional cost and reputational damage for the brand. Many services are just not designed to accommodate these unique multi-user needs, and create tension, stress and frustration in the caring experience.

We see a real opportunity to improve how these informal caring networks access essential services, so informal carers can focus more on the needs of the ones they care for, rather than navigating failure demand in services that are just not quite right in how they are designed to meet their needs. I hope you find the report insightful and the findings useful to your organisation. We look forward to your feedback and engagement.



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Section 1: What we did:

# Introduction and Methodology



# Introduction

Caregiving is a reality most of us will face at some point in our lives, be it by becoming caregivers ourselves, supporting one, or requiring our own support.

In the UK there are estimated to be over 10 million informal carers (one in five adults)<sup>1</sup>

The Department of Health and Social Care defines an informal carer as “Someone who provides unpaid help to a friend or family member needing support, perhaps due to illness, older age, disability, a mental health condition or an addiction, as long as they are not employed to do so.”<sup>2</sup>

However, our research into the lived experiences of carers suggests that this definition barely scratches the surface. Carers don't just tend to health; they assume a kaleidoscope of roles – financial consultant, advocate, administrator, emotional pillar, household lead, transporter, and legal advisor.

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1. Carers Week. (2022). Making caring Visible, Valued and Supported. Retrieved from [https://www.carersweek.org/media/af0p5u4t/carers-week-2022-make-caring-visible-valued-and-supported-report\\_final.pdf](https://www.carersweek.org/media/af0p5u4t/carers-week-2022-make-caring-visible-valued-and-supported-report_final.pdf)
  2. Department of Health and Social Care. (2016). How can we improve support for carers? Retrieved from [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/713695/response-to-carers-call-for-evidence.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713695/response-to-carers-call-for-evidence.pdf)

## Greater understanding and support is urgently needed for carers from across sectors

With up to 600 people resigning daily from their jobs<sup>3</sup> to care for loved ones, the ramifications extend to lost income, reduced savings, and pension gaps, along with other wider economic implications. Moreover, caregiving introduces significant emotional and physical strain leading to decreased quality of life. A staggering 71% of UK informal carers report poor physical or mental health<sup>3</sup>, with 55% saying they suffer from depression as a result of their caring role<sup>4</sup>.

Whilst it is important to recognise the efforts made in the health and social care sectors to address these issues, these sectors are also facing unprecedented pressure and constraints. This stifles progress and innovation and often means that design approaches that could ensure provision of support is accessible to all – such as inclusive design and co-production with community and voluntary partnerships – is de-prioritised.

## Responsibility for the support of carers does not just sit within health and social care

Informal carers are often invisible to organisations across sectors, meaning their needs are not being met by the wide array of services they need to interact with. Improving access to services will in turn improve the lives of older people and their carers, keep people healthy and independent in the community, and enable some carers to stay in work.

**We believe a human-centred design approach, working alongside those with lived experience of caring, can inspire ideas for change.**

In this report, we not only delve into the lived experience of informal carers to understand what is truly needed to support them and the people they care for, but also provide some tools and future design prompts with the hope we can accelerate this change.

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3. HM Government. (2008). Carers at the heart of the 21st century families and communities. Retrieved from <https://www.gov.uk/government/publications/the-national-carers-strategy>

4. Carers UK. (2015). State of Caring 2015. Retrieved from <https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2015>

# We took a mixed methods approach to research

## Desk Research

An exploration of how health and social care for older people is structured within England and Wales, and existing research and insight.

## 41 in-depth interviews with older people, informal carers and health care professionals\*

### Stakeholder interviews (subject matter experts)

Interviews with stakeholders who are immersed in different aspects of health and social care for older people/patients, to learn more about current priorities and challenges.

### Healthcare professional interviews

Interviews with professionals working in health care, social care and charities/NGOs, to understand their perspective and experiences.

### Older person and carer interviews\*\*

Interviews with older people and their carers to find out how they feel about access to services and understand their lived experiences.

## 1025 survey answers

(618 citizens aged 65+ years and 407 informal carers)

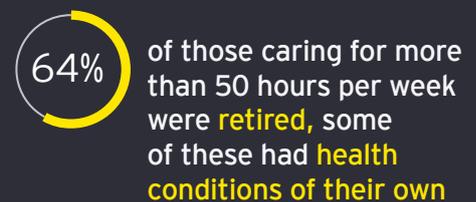
Quantitative survey among older people and informal carers in England and Wales exploring their experiences of accessing health and social care.

\*Research covered England and Wales only.

\*\*We collaborated with Alzheimer's Research UK who supported the recruitment of carers.

## Survey participants

Through our survey we collected feedback from a varied group of unpaid carers





Section 2: What we found:

# Themes and Insights



We identified **three** key themes

1

## Lost

Anyone can feel lost in the elderly health and social care landscape, even those with high levels of health literacy, self-confidence, and privilege.

2

## Unrecognised

The full extent of the caring experience needs to be recognised to ensure services meet the needs of carers.

3

## Overlooked

Who cares for the Carers? The health and social needs that are being overlooked.

# 1

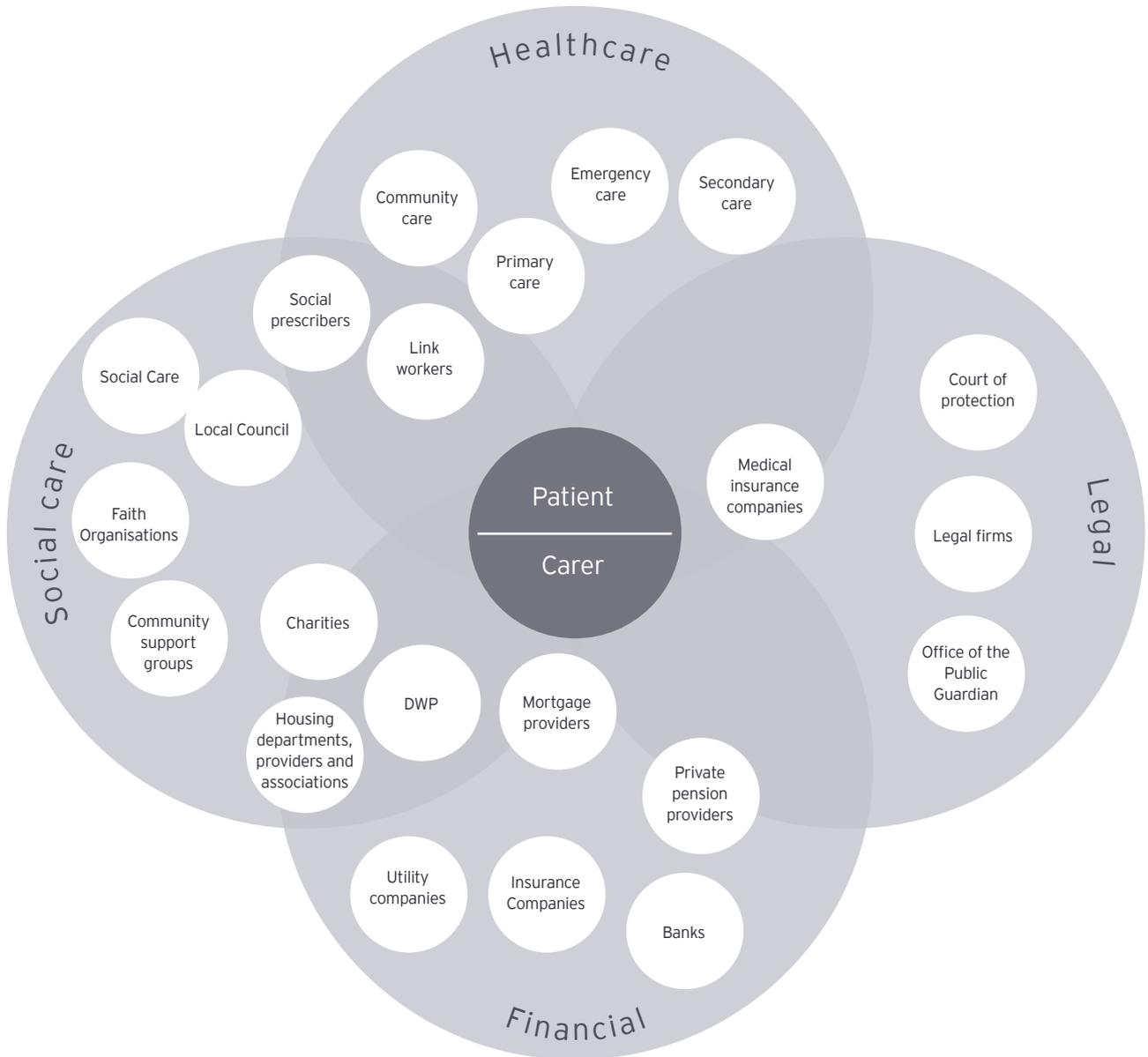
## Lost:

Anyone can feel lost in the older age health and social care landscape, even those with high levels of health literacy, self-confidence and privilege

Carers reported feeling left on their own to navigate the health and care system with very little signposting, whilst also navigating high emotions due to concern for their loved ones. Difficulty with identifying what support is available locally and how to access it was a consistent experience across all of the people we spoke to, even those with experience working in the NHS.

Informal carers, and the older people they care for sit at the intersection of a vast array of healthcare, social care, financial and legal services. Awareness, understanding and the capability to access these services are needed for the older person to live as healthily and independently as they can.

The organisations, departments and individuals that need to be interacted with are illustrated below:



“

With dementia there’s a total lack of support, you’re given the diagnosis and told to get on with it. There’s no care for the person with dementia or the carer of that person.

Carer for parent, female

“

Having worked as a Junior Doctor, I can only hope I would be able to find care for my parents when the time comes.

HCP, female

“

You’d think accessing support would be easy as I worked for an organisation that deals with the disease, but is not.

Carer for parent, male

# Despite information overload, caregivers feel under informed, with limited tools to manage their responsibilities

Diagnosis and treatment pathways for progressive conditions such as dementia are often convoluted and overwhelming, leading to delays in disease identification and subsequent care. While families are inundated with generic leaflets and brochures about support, pinpointing relevant aids for their unique situations can feel impossible. Many carers reported needing multiple physical ring binders to navigate and keep track of all this information. This palpable lack of clear, relevant guidance that supports them to coordinate care not only breeds uncertainty and anxiety but also prevents many from accessing the right support.

“

We walked out with a bundle of booklets and were left to approach charities to understand what was happening

Carer for parent, female

“

Signposts for things like funding are diabolical

Carer for spouse, male

“

Not only it is hard to find the right people, but they make it difficult to access them once you know who to contact

Carer for parent, male



## The lived experience: Meet Fadel

We had noticed my dad's memory was getting worse for a few years, so we took him to his GP who referred him to the Memory Clinic. The referral took a while to come through but once we were seen they pretty quickly diagnosed him with dementia. As we left the appointment they handed us a pile of leaflets that we needed to go through to figure out what was next.

I was really surprised that over the next few weeks and months no one checked in on us, we were pretty much left on our own. I had no experience of the social care system, so I had to spend a lot of time figuring out where to go.

When it got to point where my dad needed to go into a home we were so worried about how to fund it. Late one night I happened to see a post on a forum I'm part of that talked about how you can get care home funding for certain existing health conditions, one of which my dad has! I have no idea how we would have funded it otherwise. **There was just no support for figuring all of this out.**

# Greater access and awareness is needed for valuable services

Older age people and their carers reported that charities and community-based services such as social prescribers were highly valuable in helping them to navigate and access support, when they were made aware of them. However, few people we spoke to were aware of these services, with community services also reported as being challenging to access. There is a 'postcode lottery' in terms of what care is available and how easy it is to access, which leaves some people stranded with appropriate care in place - reported as being a particular challenge in more rural areas. Alarming, even health professionals we spoke to were unaware of the comprehensive support available in their areas.

Without a trusted, centralised source pointing towards key publicly funded, charitable, and voluntary services, carers spend an excessive amount of time piecing together information using word-of-mouth or unofficial channels, which may be inaccurate.

“

GP gave mums details to the social prescriber, who then sent mum a letter saying she can help with fees, getting funding e.g. pension credit.

Carer for parent, female

“

The social prescriber told us about sessions up at the local village hall to get transport, hot meal, activities for elderly who are isolated. Also dial a ride services through council. But a lot of other services, like day care, are more charity based, not sure if this is council funded or privately paid for.

Carer for parent, female

“

If you live close enough to a PET scanner you can get a proper diagnosis, otherwise it's just "go home".

Carer for parent, male

“

I refer people to our local branch of Age UK, they can provide financial advise but people are not aware of this.

HCP, Care Advisor

# The intricacies of legal frameworks leave carers feeling scrutinised and powerless

The process of being granted a Lasting Power of Attorney (LPA) over the care and finances of someone else is not designed to deal with the evolving circumstances of the person being cared for.

Many families, due to a lack of proactive guidance or awareness, postpone securing an LPA until a loved one's cognitive decline makes it too late. When this decline compromises the individual's comprehension and decision-making, obtaining an LPA is typically not possible. This leaves them trapped within a rigid system, primarily designed for protection. Without an LPA, caregivers are forced into the deputyship route, a process that is not only financially taxing but also demands painstaking justification for every decision.

Beyond adding to the already burdensome paperwork surrounding care, the emotional toll is significant. Carers frequently described feelings of helplessness, frustration, and guilt. Moreover, the delayed legal processes and potential disputes among family members about decision-making roles can strain relationships at a time when unity is most needed.

“

I feel like a criminal. Suddenly I'm someone that needs to be kept an eye on because I might be a threat to my own wife [...] have to report every expense of my wife, right down to her toothpaste.

Carer for spouse, male

“

I filled out the power of attorney forms and took it to the GP. He wouldn't sign as he didn't have the mental capacity.

Carer for spouse, male

“

Unbelievably, many care providers communicate by phoning the person with cognitive impairment telling them to “come in at 10am on Thursday” [...] can you see a flaw in that?!”

Carer for spouse, female

“

I would recommend getting the power of attorney in early and having that discussion whilst there is still reasonably cognitive reserve [...] It is a nightmare, It creeps up on you and before you know it you're in a situation where you need help.

Carer for mother, male



## The lived experience: Meet Leena

My husband was diagnosed with dementia and he is deteriorating slowly. When his cognitive abilities started getting noticeably worse, I decided to arrange for a Lasting Power of Attorney. I set the process in motion, but unfortunately when we got to the stage where our GP had to co-sign the form, he felt my husband did not have the mental capacity anymore to give consent. This meant I had to go through another route in order to manage all the finances and I obtained a Deputyship.

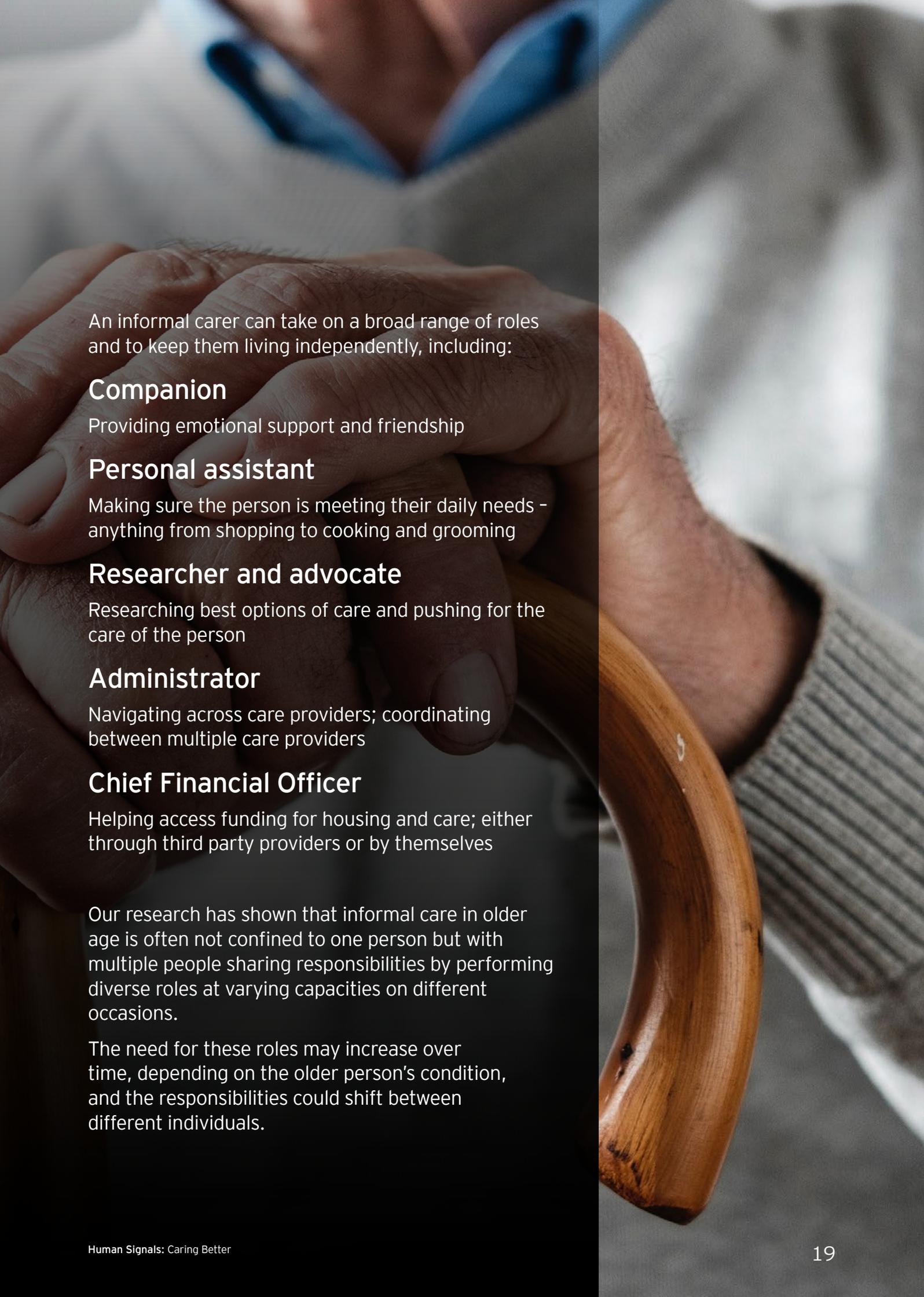
The process for this included intrusive assessments and now requires me to submit annual reports stating in detail what I am spending the money on for my husband. All of this makes me feel like a criminal rather than someone who has the best intentions for my husband's wellbeing. **If only I had known what to do sooner, we wouldn't be where we are now.**

# 2

## Unrecognised:

The full extent of the caring experience needs to be recognised to ensure services meet the needs of carers

The role of informal carer is a position that is not well understood or truly accounted for by most organisations that carers need to interact with. Carers report taking on a broad spectrum of tasks and responsibilities on behalf of the person they care for, ranging from companionship to financial management - and these are all needed for an older person's mental and physical health, and to keep them living independently.



An informal carer can take on a broad range of roles and to keep them living independently, including:

### **Companion**

Providing emotional support and friendship

### **Personal assistant**

Making sure the person is meeting their daily needs - anything from shopping to cooking and grooming

### **Researcher and advocate**

Researching best options of care and pushing for the care of the person

### **Administrator**

Navigating across care providers; coordinating between multiple care providers

### **Chief Financial Officer**

Helping access funding for housing and care; either through third party providers or by themselves

Our research has shown that informal care in older age is often not confined to one person but with multiple people sharing responsibilities by performing diverse roles at varying capacities on different occasions.

The need for these roles may increase over time, depending on the older person's condition, and the responsibilities could shift between different individuals.

# Pressures on informal carers leave them less able to engage with services or provide emotional support

Carers report spending a disproportionate amount of time securing appropriate medical support. They frequently encounter dismissive attitudes, where symptoms, especially those of dementia, are misattributed to mere ageing or relationship concerns. One carer shared that his mother was told she wouldn't receive funded treatment, favouring younger patients for better "return on investment." Such experiences force carers into an unnecessary pursuit of further or alternative medical attention on top of other administrative tasks.

Coordinating care so that older individuals can live independently for as long as possible extends beyond the medical realm; it also involves navigating legal, housing, social and financial domains. Our research identified that each of these domains presents its own intricate processes, which often do not cater effectively to proxy users (informal carers acting on behalf of the elderly individual) and those experiencing high levels of emotional and time pressures, which can act as a barrier to services.

Carers reported that this stress makes them feel less able to provide care and emotional support or to further navigate complex systems. They worry that they will make a mistake that will negatively impact the person they care for.

“

We were meant to get a review and put a plan in place for what support / contribution we needed — this was a painful process that took about six months for someone to come, lots of pull outs and sickness.

Carer for parent, male

“

I was told you need to stop being a carer, and start being a son again...

Carer for parent, male

“

“I'm competent but I'm broken by it [...] There's no joined up thinking between any of them”

Carer for parent, female

“

Lots of these organisations said they didn't have the funding for elderly people and focused on younger.

Carer for parent, male

# Transitions between service providers are key points of strain for older people and their carers

Transition moments in elderly care, triggered by changes in health status or following discharge from hospital, represent the most significant challenges for informal carers. There are often significant delays in accessing and securing the right support due to the complexity of coordinating services, exacerbated by system inefficiencies and resource constraints. Delays in securing the right community care can mean older age people becoming stuck in hospital or other temporary accommodation when it would be more efficient and beneficial for them to go home.

Carers reported challenges with the transfer of information between providers, with fragmented communication channels resulting in critical patient details being overlooked. Consequently, informal carers feel responsibility to bridge these gaps; not only recalling detailed medical histories, navigating complex paperwork, and decoding medical terminology but also assuming additional medical caregiving tasks. This added responsibility is driven by a heartfelt commitment to expedite the return of elderly individuals to the comfort of their homes, but can lead to feelings of overwhelm.

Challenges were also reported for other services that carers needed to access on behalf of the person they care for, including significant difficulty with supporting transfer of accounts to new energy, telecoms and insurance providers. In many instances, carers reported having to abandon the transfer, adding to the financial burden of the person they care for.

“

The system doesn't meet the evolving needs of my mother.

Carer for parent, female

“

It made me feel completely broken and alone and desperate, when social services weren't working for me.

Carer for parent, male

“

When thinking about transition moments, our survey showed that older people and their carers were most worried about:

1. Time it takes to set up new support, treatments or care
2. Ease of contacting care providers
3. Regular reviews are set up
4. Responsiveness of care providers
5. Information on benefits or care allowances that can be claimed

Quantitative survey results



## The lived experience: **Meet Gaston**

Hi, I'm Gaston, my mum has a progressive lung condition and arthritis . Being older she has started to experience falls and needed a new knee, She was referred to Social Care for an assessment to establish her care needs. After 6 months we are still waiting for the review to take place.

Unfortunately there was another fall and she broke her neck. She needed a neck brace and was prescribed morphine by the consultant who was not aware of her history and that she was already on morphine. This additional morphine would have caused a medical emergency. **I now feel under huge pressure to be responsible for my Mum's safety and continuity of care when going to medical appointments.** I have developed a summary of her medical background and medication which I bring to all appointments and ask doctors to read first before we start. I update it before each new appointment.

# 3

## Overlooked:

Who cares for the carers?

The health and social needs that are being overlooked

Caring is well known for creating emotional, physical, financial, and mental strain for those who do it and yet services across the health and care ecosystem and beyond often fail to take carer's needs into account. There is mounting evidence that caring is a social determinant of health, which can cause the carer to have worse physical and mental outcomes, adding to the burden on the health and care system in the long run.

Despite being key to the provision of care and a linchpin for the system, carers often have to rely on informal communities and their own willpower to make sure their loved ones are cared for.

“

Fight your corner because no one else is going to do it for you.

Carer for parent, female

# The pressures of caregiving can lead to deteriorating physical and mental health of carers

Carers can lose sight of their own needs due to their desire to take care of their loved one and the pressures this comes with. Carers reported feeling intensely alone and isolated, expressing feelings of abandonment and limited ability to prioritise their own wellbeing. Respite care is important and beneficial for the wellbeing of the carer, however carers felt the necessary resources are rarely available to pay for alternative care. This can in turn be detrimental to the care they are then able to provide.

While not usually the desired outcome, some carers we spoke to reported that when the person they cared for moved into a care or nursing home, they felt able to become a spouse, son or daughter again and to regain some of their personal identity.

“

I was told you need to stop being a carer, and start being a son again...

Carer for parent, male

“

It's very difficult to care for someone with dementia. It's awful and it continues all night, so you are knackered yourself. It's not understood that you need a lot of help from people in the community. We need support for the carers and people who are looking after them.

Carer for spouse, female

“

If I could have only had a phone call every three months from the GP or nurse, just to feel someone was showing some interest.

Carer for spouse, female

“

My brother found me respite care which I found very helpful.

Carer for spouse, female



## The lived experience: Meet Sandra

Keith and I have been married for 50 years and Keith was diagnosed with dementia 7 years ago. Since Keith's mental capacity deteriorated, I have been a full-time carer for him. The physical care can be hard, but I am getting support from social care assistants who come in every day to help with the daily routines. I had a part time job but had to give it up because I had to be there for Keith 24/7. I often feel overwhelmed as I grieve for my husband and now I am responsible for his care it has changed our relationship, from wife to carer.

I need to spend a lot of time keeping on top of paperwork, with shelves full of ring binders relating to care workers, medical appointments and medication Keith is on. On top of this, although there is information about additional care or support services available, it is difficult to navigate through this and find out what is best for me and Keith. **All of this takes so much and means I have less time to connect emotionally with my husband and absolutely not time for myself.**

# Lack of early individual preparation for old age intensifies caregiving responsibilities

Ageing well necessitates proactive preparation. Our research indicates that individuals who proactively plan while still being healthy and cognitively intact face fewer hurdles in accessing care and managing daily practicalities. However, many expressed regret that they were never aware of whether or how to prepare for older age. While there have been notable efforts to shift public perception about the importance of pension savings, exemplified by public awareness campaigns such as the roll-out of the Pension Act 2008 in 2012, this effort is not broad enough to address factors such as care costs.

A lack of preparation places a higher administrative burden on informal carers when it's most needed, detracting from the time they could spend providing emotional support.



## The lived experience: Meet Janet

I am Janet, and I live in a rural village with my dog. I was diagnosed with heart failure 10 years ago and have recently been diagnosed with lumbar spinal stenosis, giving me horrendous pains down my hip and legs. Initially when I was diagnosed I could manage the pain but I had a fall a few months ago which made it worse. A while back I was visited by a charity worker a few times a week but this stopped abruptly after funding in my area was pulled.

There is no taxi service or individual mobility service available where I live. My friend comes around and does gardening and cooking for me. **Because of the rural location there aren't many care services available, there are no check-ups so really I'm totally dependent on my friend.**



Section 3: Thinking differently:

# Workshop tools to help you design your service for informal carers

# Workshop Tools to help you design your service for informal carers

We have distilled our research into a set of tools that can help you understand what informal carers may need from your service, how to design with them in mind, and finally how you could reimagine your service experience.

## Carer personas

Four types of informal carers that demonstrate the different needs and behaviours that services need to work for.

## Design principles

A set of guidelines to ensure services work for older people and their informal carers.

## Future design prompts

Challenges for how services could be reimaged to more creatively meet the needs of informal carers.

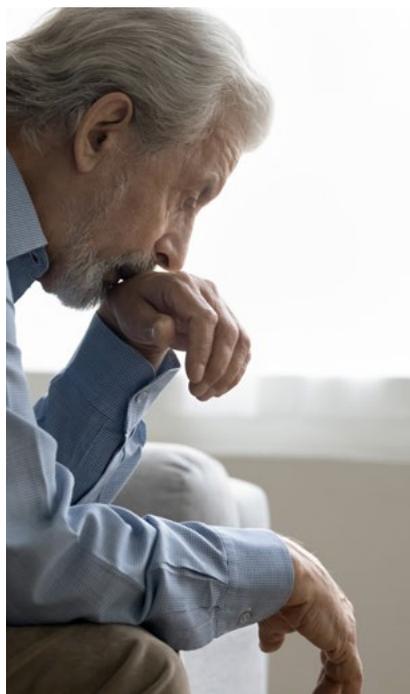
# Informal Carer **personas**

We discovered that the behaviours and needs of informal carers when accessing services was highly influenced by two factors: **how proactive they were about finding information and resources, and how confident they were in their own abilities to navigate new services and problem-solve.** Based on this, informal carers can be grouped into four key archetypes that demonstrate the variance in needs and behaviours that need to be understood and designed for.

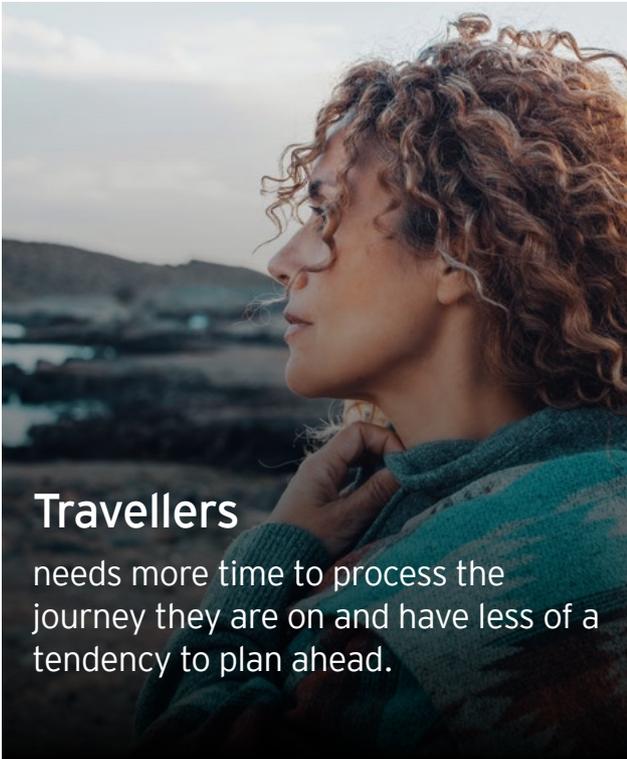
This page shows a summary of these informal carer personas. On the following page we include persona cards for each, showing their needs, behaviours and some 'how might we' prompts to help services more effectively meet the needs of these groups.

These persona cards can be used to reinforce the focus on informal carers in workshops:

- ▶ Discuss the personas at the start of a workshop to ensure everyone has their needs at front of mind
- ▶ Throughout the workshop, refer back to the personas to ensure proposed solutions cater to the needs of these groups
- ▶ Leverage the personas during discussions and decision-making, asking questions such as "Would this approach work for Drifters?"

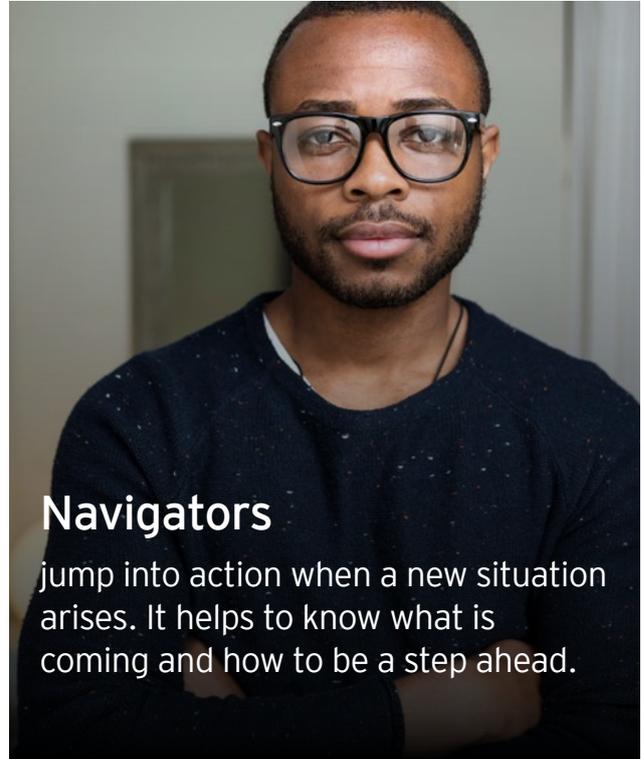


## The four carer personas:



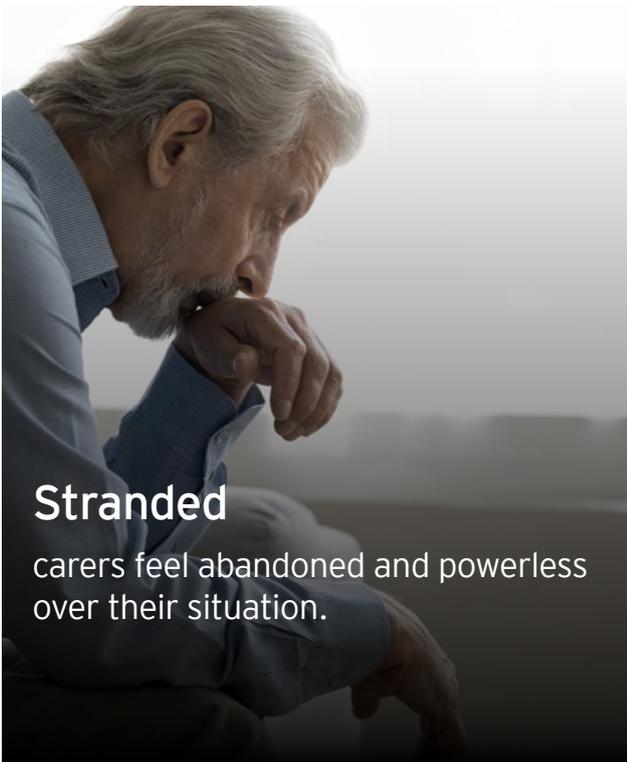
### Travellers

needs more time to process the journey they are on and have less of a tendency to plan ahead.



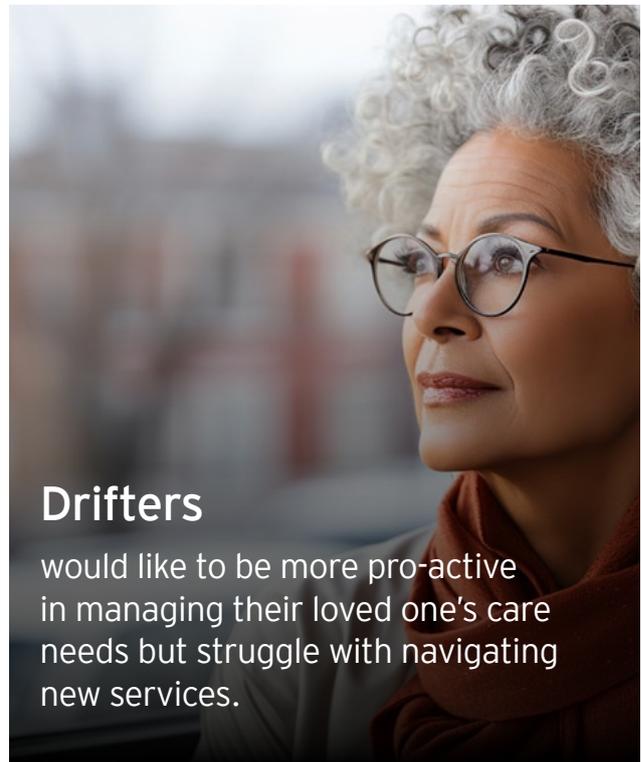
### Navigators

jump into action when a new situation arises. It helps to know what is coming and how to be a step ahead.



### Stranded

carers feel abandoned and powerless over their situation.



### Drifters

would like to be more pro-active in managing their loved one's care needs but struggle with navigating new services.

Confident

## Travellers

“

Let's see what happens but deal with what is happening now first

The Traveller needs more time to process the journey they are on. They have less of a tendency to plan ahead, with their focus on helping their loved one in the here and now.

The Traveller is resourceful and will investigate and take action as needs arise. This means they may miss opportunities to prepare effectively for the future.

How might we make Travellers aware of decisions that will be needed for the future?

How might we help Travellers to prepare for the future without overwhelming them?

## Navigators

“

I'm a bit like a dog with a bone

The Navigator jumps into action when a new situation arises. It helps to know what is coming and how to be a step ahead.

The Navigator is persistent, highly organised and is constantly looking for more information, services and support. They focus on networking with as many other informal carers as they can because any new contact can lead to more advice.

How might we relieve some of the coordination and organisation pressures from the Navigator?

How might we harness the Navigator's networking skills to share information with others?

Reactive

Proactive

## Stranded

“

I just have to keep going

Stranded carers feel abandoned and powerless over their situation. Stranded carers are less likely to try or be able to find their own sources of support. As these carers can be invisible, by the time they present to organisations their care needs are often very high.

Access to services often starts online which they may find challenging, due to a lack of knowledge or access to technology, less experience of services or lower levels of literacy.

How might we identify Stranded carers to provide them with support?

How might we engage them using a strengths-based approach to build their sense of empowerment?

## Drifters

“

I do my best but would like someone to be there with me

Drifters would like to be more pro-active in managing their loved one's care needs but struggle with navigating new services.

Drifters thrive when they find a person or organisation that can give them the time to lead them through the system. However, when the source of help, care or advice has 'dried up', they feel like they are back to square one.

How might we provide Drifters with a 'map' of the service so that they know where to go next?

How might we give Drifters enough confidence in their understanding of a service for them to self-serve?

Unconfident

# Design principles for services for informal carers

We have consolidated our research into a set of design principles, These really boil down to good design practises, as what will work for those who are experiencing the extremes of emotional, physical and time pressures should work for the majority.

In workshops these can be used to:

- ▶ **Assess the suitability of services:** Use to guide a discussion around whether a service adheres to these principles and where there could be improvements to the service experience.
- ▶ **Generate ideas:** Use as sources of inspiration, encouraging workshop participants to generate ideas that align with and support the outlined design principles.
- ▶ **Sense-check solutions:** Ensure proposed designs are in line with the core values and objectives expressed in the principles.
- ▶ **Guide collaboration:** Use to foster alignment among participants on the fundamental aspects that should underpin service design.

## We believe that services across all sectors should be:

**Accessible** to all across all interactions and touchpoints

**Supportive:** acknowledge the emotional and practical load placed on informal carers and be there to assist and support

**Integrated:** bring multi-organisation service responses together seamlessly around the older person and informal carer

**Communicative:** understand users to communicate the right information at the right time

**Simple:** remove unnecessary steps, processes and bureaucracy

**Flexible:** adapt to the needs and context of users

## Design Principles for services for informal carers (1/2)

### Accessible

to all across all interactions and touchpoints

In the context of care, the definition of accessibility in services should be expanded to take into account the shared responsibilities of informal carers.

- ▶ Make services easy to find by providing consistently signposted 'front doors'.
- ▶ Leverage multiple touchpoints to enable older people or informal carers to easily access or transition into your service.
- ▶ Facilitate smoother interactions and ensure accurate support for both older people and informal carers.

### Supportive

acknowledge the emotional and practical load placed on informal carers and be there to assist and support

The caring process is often emotional and overwhelming. Services should be designed with this in mind.

- ▶ Support the cognitive and emotional load of the informal carer through positive interactions and proactive updates.
- ▶ Support informal carers with information and paperwork.

### Integrated

bring multi-organisation service responses together seamlessly around the older person and their informal carer

Through increased collaboration between various services and stakeholders, access and delivery of service can be improved, and costs decreased through operational efficiency.

- ▶ Find out where user journeys intersect with different actors or agencies and eliminate dead ends.
- ▶ Build mechanisms to allow older people and informal carers to keep track of records and allow for data to be handed over between organisations.
- ▶ Encourage collaboration and consistency; sharing best practise between different providers or regions.

## Design Principles for services for informal carers (2/2)

### Communicative

understand users to provide the right information at the right time

The caring journey is long and requires consistent adaptation to changing needs; maintaining an open dialogue with users is crucial.

- ▶ Maintain a dialogue with your users to keep up with their changing needs.
- ▶ Pre-empt their needs whenever possible, help your users prepare for next steps, and let them know where they are in the journey.

### Simple

remove unnecessary steps, processes and bureaucracy

Caring is already challenging; administrative processes should be simplified to accommodate people's needs.

- ▶ Leverage collaboration with different agents to share information for identity and eligibility checks.
- ▶ Enable multiple channels of communication when both the older person and informal carers need information or to amend support.
- ▶ Create multiple levels of delegation of power. Only require lasting power of attorney when essential.

### Flexible

adapt to the needs and context of users

The context of caring is complex; rigid policies and minor obstacles can hinder journeys.

- ▶ Co-create directly with older people and informal carers and design with relationships in mind – your end user might be different than expected
- ▶ Explain clearly how and why decisions have been made, and provide users with further options.
- ▶ Make sure your systems have fail-safes. Design with exceptional cases in mind.

# Future **design prompts**

Based on our research, we pose four questions to challenge how we think about the issues raised. These can help push thinking and inspire ideas for how services can be reimagined to meet the needs of informal carers.

These prompts can act as catalysts for innovative thinking within a workshop:

- ▶ **Workshop warm up:** Ask participants to quickly generate as many ideas as possible using the prompts and 'What if' examples towards the beginning of a workshop to encourage them to think creatively.
- ▶ **Idea generation:** Use the prompts as focal points for brainstorming sessions, encouraging participants to generate ideas around each prompt as a way to direct attention to aspects of a service that could have a big impact for informal carers.

# 1

## Prepare proactively

How might we shift the timeline forward and better prepare individuals for inevitable caring responsibilities?

# 2

## Improve transitions

How might we use partnerships to prevent people falling through the cracks?

# 3

## Reimagine policy frameworks

How might we iterate policies based on lived experience to better reflect the people they need to serve?

# 4

## Care for carers

How might we proactively identify those who need better support?

# 1

## Prepare proactively

How might we shift the timeline forward and better prepare individuals for inevitable caring responsibilities?

Individuals and families who prepare well for the realities of older age have substantially better experiences, but these individuals are the exception to the norm. Rethinking how individuals and families prepare for older age responsibilities is key to improved outcomes for all.

### What if we created new ways to share responsibility?

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**Imagine intergenerational elderly care bank accounts.** What if an intergenerational financial hub or account was introduced where family members across generations could contribute toward future elderly care savings. This account could also facilitate 'gratitude rewards', subtly offering recognition and financial support for carers to take opportunities to rest and rejuvenate. Additionally, it could come with features like automatically reporting care expenses to the Office of the Public Guardian.

### What if we leveraged current customer/company relationships?

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What if legal, healthcare, utilities and financial services evolved to assure individuals 'We are with you for the long haul', helping them consider and draft their future preferences early with periodic reviews. Well-structured plans could not only remove frictions in the caregiver's journey in the face of unexpected health dilemmas, but also offer organisations the opportunity to foster customer loyalty.

# 2

## Improve transitions

How might we use partnerships to prevent people falling through the cracks?

The provision of care relies on the coordination between multiple different organisations and stakeholders. Multi-agency collaborations can distribute responsibility, decreasing the amount of bottlenecks and burdens in the system, ultimately creating opportunities for better delivery of care.

### What if we used data to anticipate future needs?

**Imagine Connected early diagnosis prediction.** What if we could harness today's technological advances of real-time data, AI, and predictive analytics. Just as analytics foresees credit defaults or deduces life milestones like pregnancies from spending habits, we could identify those on the brink of social isolation or cognitive health decline, ushering in timely interventions.

### What if we re-purposed existing touchpoints?

**Imagine if pharmacies became community hubs.** What if we could transform pharmacies into pivotal community hubs for holistic elderly care and supporting key transition moments. Instead of a hospital bed-blocking wait for prescriptions, these could be seamlessly delivered home, facilitating smoother transition from hospitals. The full potential of pharmacists could be realised to support with long term conditions through medication management, testing and holistic preventative healthcare, or minor ailments.

### What if we shared resources across organisations?

**Imagine extending care partnerships.** What if care partnerships could be extended to involve everyday community touchpoints like postal workers and grocery delivery personnel in care. A system where these regular visitors, trained with a simple set of observational questions, could identify early signs of need or risk. Any signs of stress could be flagged on a centralised dashboard, triggering a rapid support response from the relevant organisation.

# 3

## Reimagine policy frameworks

**How might we iterate policies based on lived experience to better reflect the people they need to serve?**

While initially created to protect people, policies and regulations such as Lasting Power of Attorney are too rigid to cater to the reality of care, often being blockers to the provision of care, not enablers. By taking into account the lived experiences and realities of carers, we can co-design better policy frameworks that enable better experiences.

### **What if we acknowledged isolation as a medical issue**

What if the signs of caregiving stress were universally acknowledged as urgent medical issues. Recognising the physical and emotional strains of caregiving would not only validate the challenges carers face, but also lead to immediate and tailored support, ensuring their well-being alongside those they care for.

### **What if we reimagined legal frameworks?**

**Imagine flexible third-party mandates.** What if older age care legal frameworks could be re-imagined and co-designed with carers and seniors, along with charity insights for real-life relevance, ensuring no bureaucratic processes stand in the way of immediate care when needed.

### **What if we shifted the timeline for big decisions forward?**

**Imagine well designed preparation communications.** What if frontline services could proactively guide informal carers and elderly individuals across sector boundaries through well-crafted content design. For instance, while managing mortgages, a gentle prompt about the intricacies of power of attorney could be invaluable, or transportation providers could inform individuals about local community clubs, paving a smoother path through the maze of elderly care logistics.

# 4

## Care for carers

How might we proactively identify those who need better support?

Carers, with their varying roles and ever-shifting responsibilities, cannot be replaced; but some of the burden they take on can be eased. With better designed services, that take into account their emotional and social needs, we can make the role of caring a little bit easier for all.

### What if we approached caring as a risk factor?

**Imagine psychosocial screening for carers' wellbeing.** What if health and social care could seamlessly detect and act upon the silent cries of isolated informal carers. With a system where psychosocial screening becomes as integral as any health checks, bridging the division and ensuring no carer ever feels left behind in performing their pivotal role. Much like screening services for health conditions, identifying caring needs early on can help provide better outcomes.

### What if we collected and curated information for carers as needed?

What if digital front doors weren't just about accessibility of information digitally but intuition and foresight. Solutions could adapt to individual situations, cutting down tedious data navigation and deliver hyper-personalised health prompts, with AI personalising memory exercises based on an individual's cognitive pattern. Instead of drowning in data to find and plan support, carers could feel empowered and equipped with crucial information at their fingertips.

### What if we brought the hospital home?

**Imagine scaling smart monitoring for independent living.** What if a fusion of medical records with monitored real-time behaviours could be used to detect irregularities, adjusting the living environment, or notifying carers when required. This would not only ensure independent living but also reduce the need for carers to sacrifice their own wellbeing from being continually physically present for high-risk elderly loved ones.



Section 4:

# Notes from the field

# Notes from **the field**



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This has been a fascinating project to work on, but due to the subject matter not always easy. It makes you reflect on your own family and feel frustrated, sad and angry on older people's and informal carers' behalf.

On this project we implemented the following practises to help ensure the research was a positive experience for both participants and our team:

- ▶ **Third-sector engagement:** We found working with Alzheimer's Research UK invaluable in finding and engaging with people who could share their lived experience
- ▶ **Informed consent:** We placed an emphasis on informed consent by making sure participants understood what the research involved and what we would do with the findings. We sent an email ahead of the session explaining what we were doing and then followed this up at the start of the interview with a clear explanation, emphasising their right to pull out of the research at any time with no negative consequences.
- ▶ **Participant wellbeing:** We wanted to make sure the research was a positive experience for participants where possible. This meant approaching the interviews in an open and fluid way, that enabled participants to only share with us what they felt comfortable talking about. This gave participants control over whether they discussed areas they may find upsetting to talk about. The people we spoke to were incredibly open and generous with their stories, and a few contacted us afterwards to thank us and to say the interviews made them feel heard. We also tried to sign-post participants to helpful information sources, such as charities, wherever possible.
- ▶ **Researcher wellbeing:** We tried to ensure that researchers could have breathing space between interviews to reset and focus on their own wellbeing. We also found it particularly important to hold daily check-ins with the team to see how they were feeling and flag wherever anyone needed support.
- ▶ **Project goals:** Throughout the project we found it helpful to keep in mind why we have been conducting this research - in the hope that future experiences may be better based on taking into account the lived in experiences of older people and informal carers right now.

# Thank you for reading

If you would like a briefing of this research or a discussion on how your teams can apply these insights, please contact Peter Neufeld and Will Shaw using the details below.

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