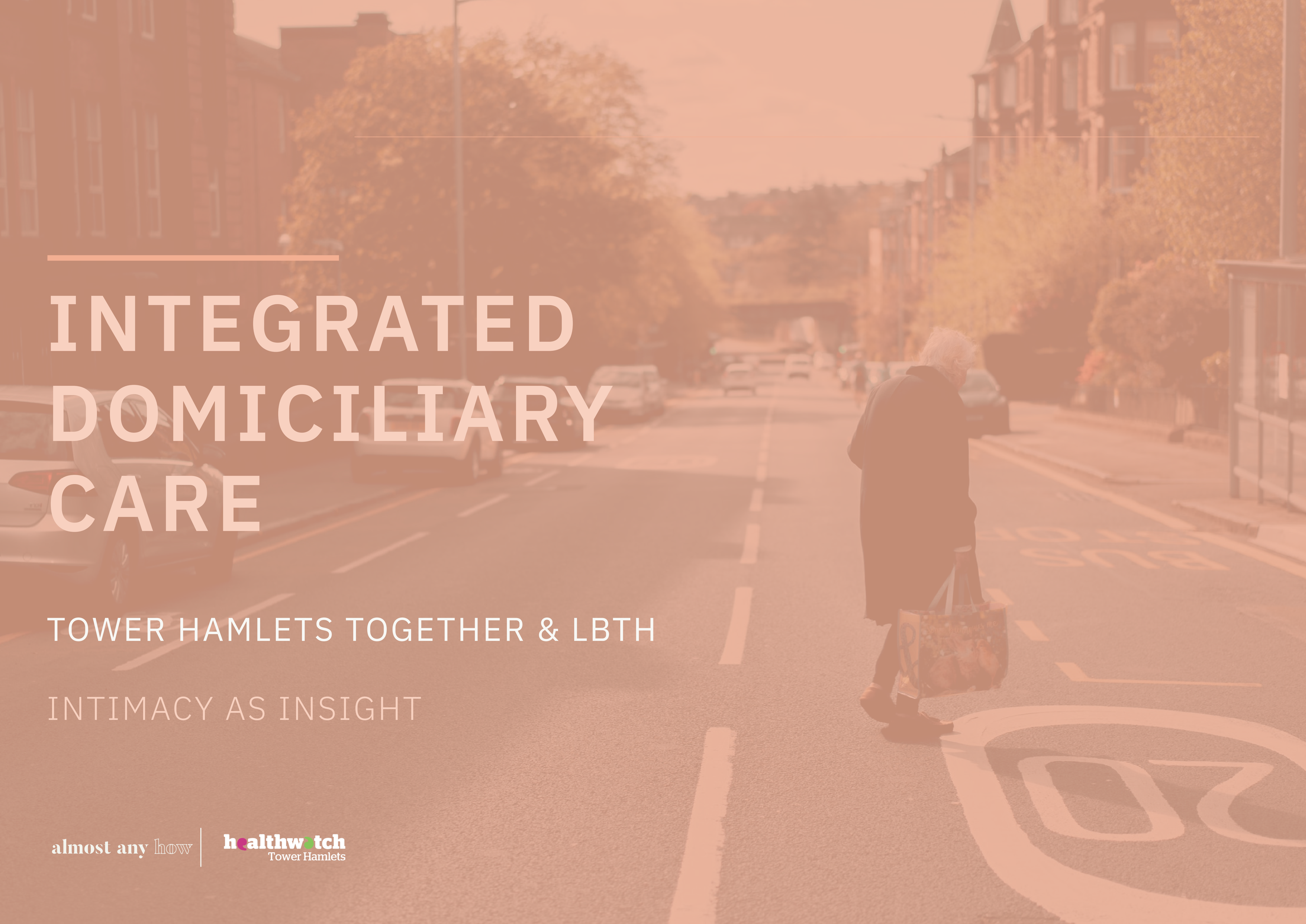


INTEGRATED DOMICILIARY CARE

TOWER HAMLETS TOGETHER & LBTH

INTIMACY AS INSIGHT

almost any how | healthwatch Tower Hamlets

> *"In Zen, the word intimate is synonymous with awakening, **realization, or enlightenment**... I prefer the word intimacy because it is an invitation to come closer, to fully embrace and lovingly engage with your life right where you are, rather than trying to move beyond it."*

FRANK OSTASESKI
FOUNDER, SF ZEN HOSPICE CENTER

THE HEAD & THE HEART

Realization or enlightenment.

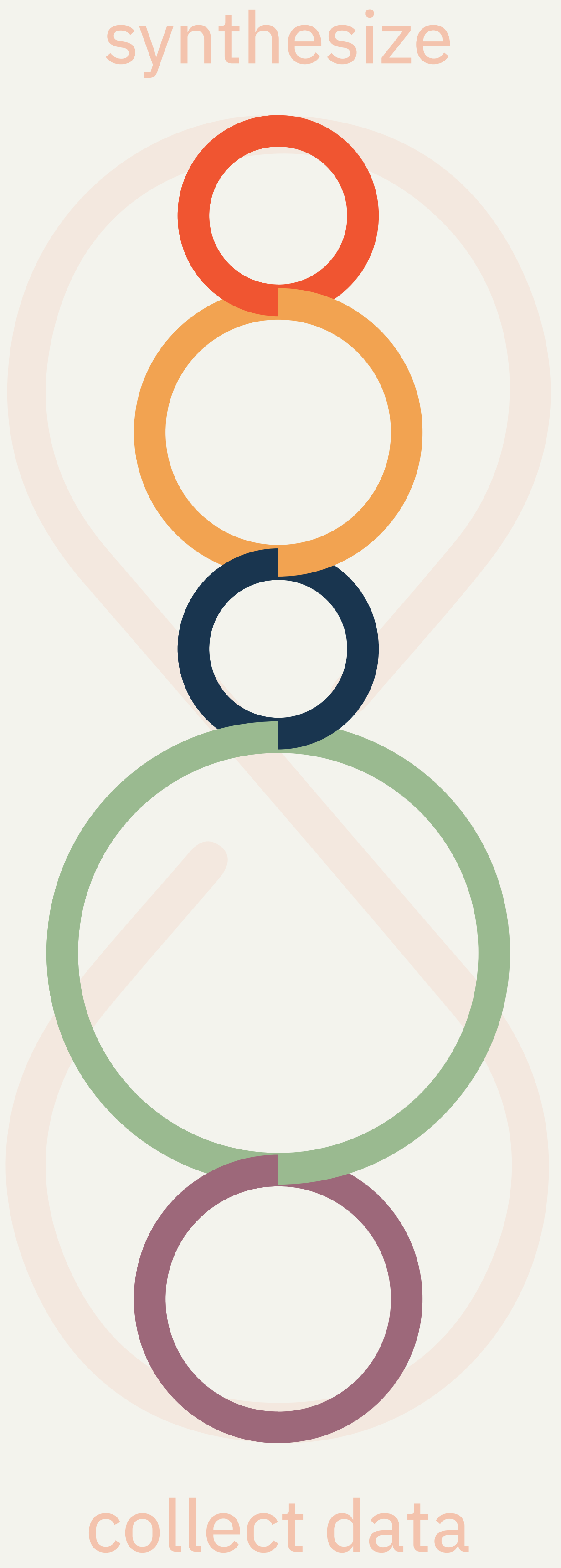
Design, from our point of view, is purely about the ability/capacity to learn, and the cycles of learning and testing, and learning again.

Frank Ostaseski co-founded and ran the San Francisco Zen Hospice project for over 30 years. In his book *The Five Invitations*, he beautifully reflects on his lessons of compassion over that time, and in the context of caring for those at their most vulnerable.

The model on this page describes the process of how we've arrived at the insights presented in this document - the intimacy described by Ostaseski by way of data and a rigorous exercise of the 'head'.

The symbol here denotes the circular, iterative and connected process of learning that we believe is necessary for quality engagement and design research - a constant loop of data collection and synthesis.

In this document, you will see plenty of quotes and citations (the purple and green circles), which have laid the foundation for the hypotheses (blue) and the reflections and synthesized ideas (yellow and red).



reflect

The hypotheses that develop strenght, the ones we believe we are hearing with some consistency, then become the key topics of discussion. We explore these realities - how do they play out? what are the implications? who is involved? what is the expression of need? and so on. This also happens while the interviews are still being conducted.

listen

Over a period of several months, we enter the lives of those we are looking to understand deeply - we are conscious of not askering for more than we can give ourselves. The method is semi-structured, ethnographic interviews, audio recorded and transcribed.

insights

The reflections combined with a continued source of new information/data (the interviews) start to surface clearer and clearer pictures of the reality of those we're listening to. Calling on previous experiences and other theories and ideas, we synthesise concepts that can frame our understanding of how we best design and move forward.

hypotheses

As we begin listening, we are also forming 'statements of reality' - thing that we believe are accurately describing the experience of those we're speaking to. We do an interview, we listen back, we start to build hypotheses. We do another interview, we refine the hypotheses, and so on.

context

Here we humbly engage those in the system (commissioners, nurses, care providers, etc.) while we carry out secondary research to start to build an understanding of what those players need, how this engagement can work best for them, and also what has been done to this point.

CONTENTS

Timeline

GRATITUDE

There's people coming regular, these people know what I need. That's it. So nurse coming and looking at the book, she check the book and medicine and everything. So carer coming and sometimes when I tell her that the bath whatever I need it. So I tell her one time and she does the same thing every time. #5

01 | CONTEXT

THE INTENTION

This project was inspired by the idea that a new and different model for home care is possible. Beautiful foresight from Healtwatch Tower Hamlets and the heads of Joint Commissioning in Tower Hamlets said that a new and different model MUST start with the user voice - the user view point.

We are grateful to be invited in to the homes of those receiving domiciliary care in Tower Hamlets to help build a deep insight about what is important to them, what integrated care might look like and how we might be able to better support their care going forward.

We began this engagement with just under 18 months before the next phase of commissioning. Our goal for the entire project was to 1. build an intimate understanding of the domiciliary care, user experience, 2. facilitate a collaborative discussion among a diverse range of stakeholders in workshop form, and 3. support more integrated and sustainable commissioning in Tower Hamlets for domiciliary care services.

“It's about understanding and getting quite a tangible picture of what joined up care looks like for those people receiving it. So we know already the stories around different numbers of people going into different visits, doing slightly different tasks when one person, in theory, could do them all. You know those kinds of things, but actually finding out from people receiving those services what that is like on the receiving end and how that could be experienced better as a joined-up piece of work.”

WARWICK TOMSETT
JOINT DIRECTOR OF INTEGRATED COMMISSIONING

“We are looking to develop a new model for home care provision fairly soon, and I guess one of the things that we wanted to think about was, actually, do we want the model to stay the same?... if we're looking at the most complex group, things like supporting people to die in their place of choice. So we've got that as an outcome indicator in some of our contracts. Things like patient activation, so we know that we really want to support people to engage in their own care. How do we encourage that? How do we monitor that?”

RAHIMA MIAH
DEPUTY DIRECTOR OF INTEGRATED COMMISSIONING & TRANSFORMATION

THE I STATEMENTS

I feel safe from harm in my community

I play an active part in my community

I am able to breathe cleaner air in the place where I live

I am able to support myself and my family financially

I am supported to make healthy choices

I am satisfied with my home and where I live

My children get the best possible start in life

I am confident that those providing my care are competent, happy and kind

I am able to access safe and high-quality services (when I need them)

I want to see money is being spent in the best way to deliver local services

I feel like services work together to provide me with good care

I understand the ways to live a healthy life

I have a good level of happiness and wellbeing

Regardless of who I am, I am able to access care services for my physical and mental health

I have a positive experience of the services I use, overall

I am supported to live the life I want

I believe the trust confidence and relationships are in place to work together with services to decide the right next steps for us as a whole community

COMMISSIONING PRIORITIES

The Tower Hamlets 'I statements' on the previous page, in many ways outline priorities in the borough for citizen outcomes.

Along with those, we've analysed and synthesised a collection of points of view on the plans, goals and intentions of health and social care going forward, those include: The NHS Long Term Plan (2019), Ageing Well in Tower Hamlets (2017), the Tower Hamlets Integrated Commissioning Aims (2018) and the THT Ageing Well Strategy Priorities (2019).

We created these 6 priorities to highlight the themes of the resources listed above - they have and will continue to give us guidance and steer.

More detail from these references can be found in the appendix.

individual

Whether it's the NHS Long Term Plan or the Ageing Well Strategy for Tower Hamlets Council, words like 'personal', 'person centred' and 'self-supporting' appear front and centre.

power

Helping others help themselves has become a rallying cry for health and social services in Tower Hamlets. Ultimately, we are describing the diffusion of autonomy.

quality

Social prescribing, care at the right place and right time and flexibility are all ways to meet people's needs and improve health, wellbeing and quality of life.

connected

Again, intimacy and moving closer - this is not only speaking about the relationship between the social worker and the user, but also the user's relationship to their wider community.

storytelling

"Good information" in 'good ways" - accessible communication and simple ways to understand, engage with and access a set of complex system.

affection

Isolation, reduced mobility and the onset of chronic illness precede grief, depression and limitations - we want to meet those feelings and thoughts head on with courage and compassion.

“…we had a family whose father was on a PEG feed and very sweetly ***they wanted all to eat together with the father at the table with his feeder****. We had complaint after complaint after complaint because the nurse came late to put the feeder, and they already had cooked, and then the nurse came too early, and they hadn't cooked, and they couldn’t do it… she came across this family, and basically kind of said, ‘well, you don't need a nurse for this’. ‘Oh no, no, no, this is technical stuff… we’ll kill him’… she negotiated with them, and it took about three weeks of training the family to put the PEG feeder. So* ***they now can eat whenever they want, and they take the feed down again and they're utterly independent****.”*

HEALTH & SOCIAL CARE PROFESSIONAL
TOWER HAMLETS

OUR GUIDING QUESTIONS

Leading up to, and working through the interviews with users, there were a series of questions that arose for us about the nature of commissioning and care, and specifically in Tower Hamlets.

Based on our discussions with commissioners, providers and nurses, and also our secondary research on care, domiciliary care and larger wellbeing strategies locally and nationally, we developed a set of questions.

These questions have multiple purposes: they are meant to guide the interviews and the research, they are there to help us step back and create some context and perspective for what we are trying to accomplish with the research, and they offer direction for any workshops and collaborative discussions we support with stakeholders.

+ What is the core purpose/intention of care? Comfort? Behaviour change? Supporting meaning? Collaborative wellness?

+ What are the collective goals and values?

+ What is joined up/integrated care?

+ How might we design a ‘better’ health and wellbeing experience for adults with complex needs? Higher quality, consistent, etc.

+ What is better? What do we want to encourage and incentivize? How might commissioning be designed to support that sort of experience?

+ How do we go from 'good' to 'excellent' care provider? How do we go from 'poor' to 'good'?

+ What might the relationship between health and care workers (district nurses, home care workers, etc.) look like?

+ How might we continue to incentivize and support collaborative discussions across stakeholders?

+ What does capacity building need to look like to deliver quality?

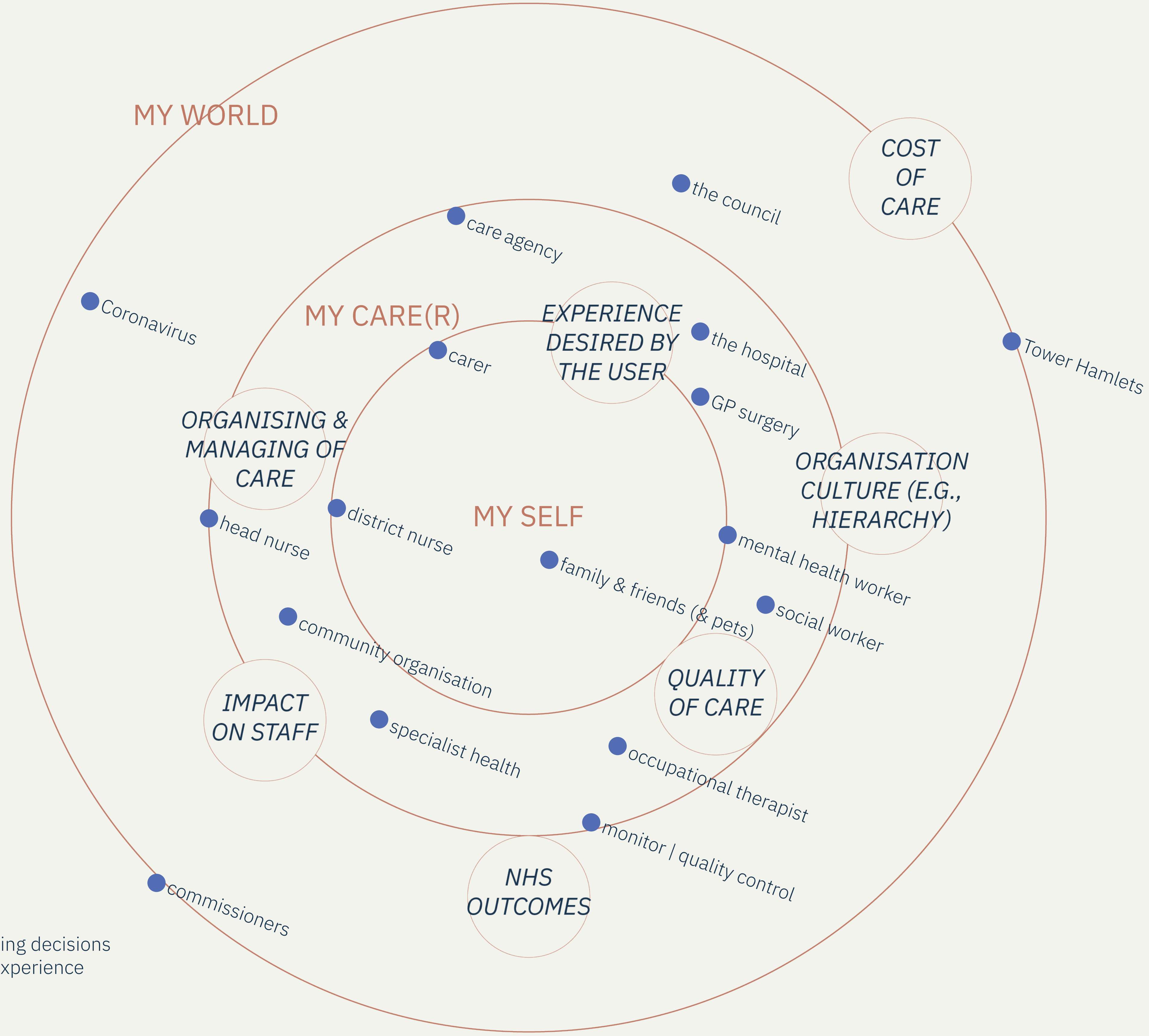
02 | WHO

A SYSTEMS VIEW

Based on what we heard from users, nurses, care agencies and commissioners, we created this snapshot of how we understand the system of health and social care.

The intention is to step back and remind ourselves of how we fit into a larger structure, the players involved and what we need to consider as we delve further into the design process.

This is a first draft, and can be edited to effectively support our design discussions with the stakeholders.



● actors

○ forces driving decisions and thus experience

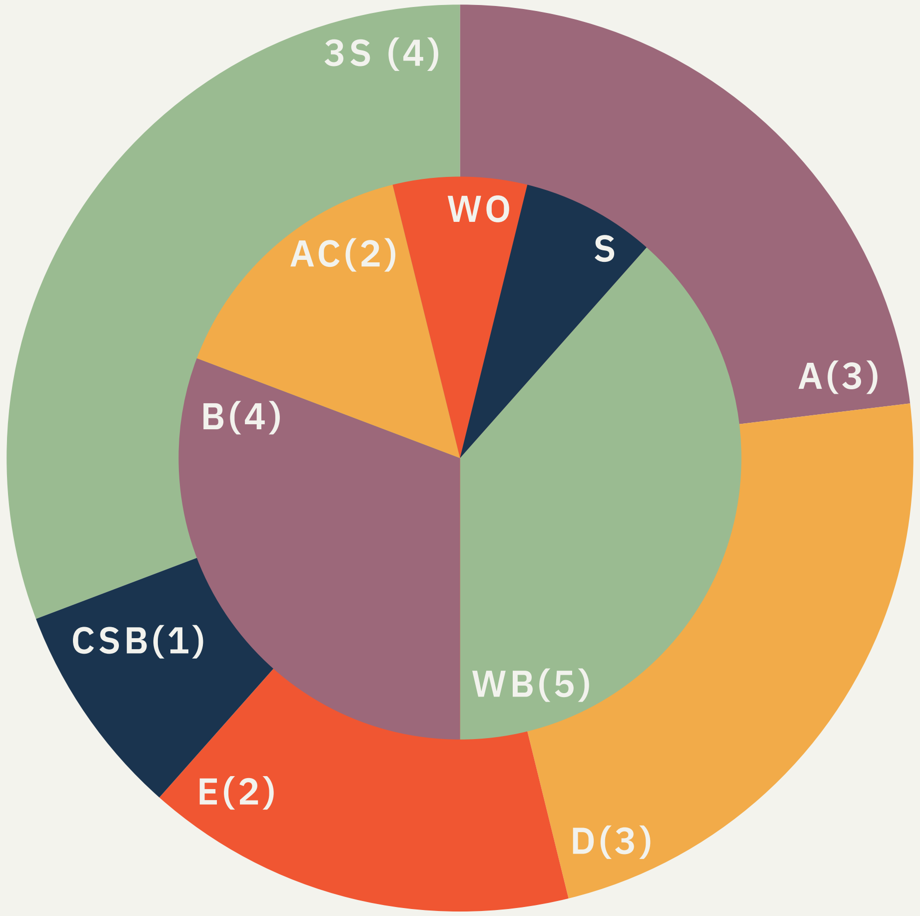
OUR USER SAMPLE

Those we spoke to have multiple comorbidity, input from GPs, district nurses, specialist services and home carers, among others. They mostly sit within the top 10-30% of the most complex cases in the borough.

We started with a target of conducting 10-15 in-depth interviews. In the end, we interviewed 13 users, and in some cases their family members.

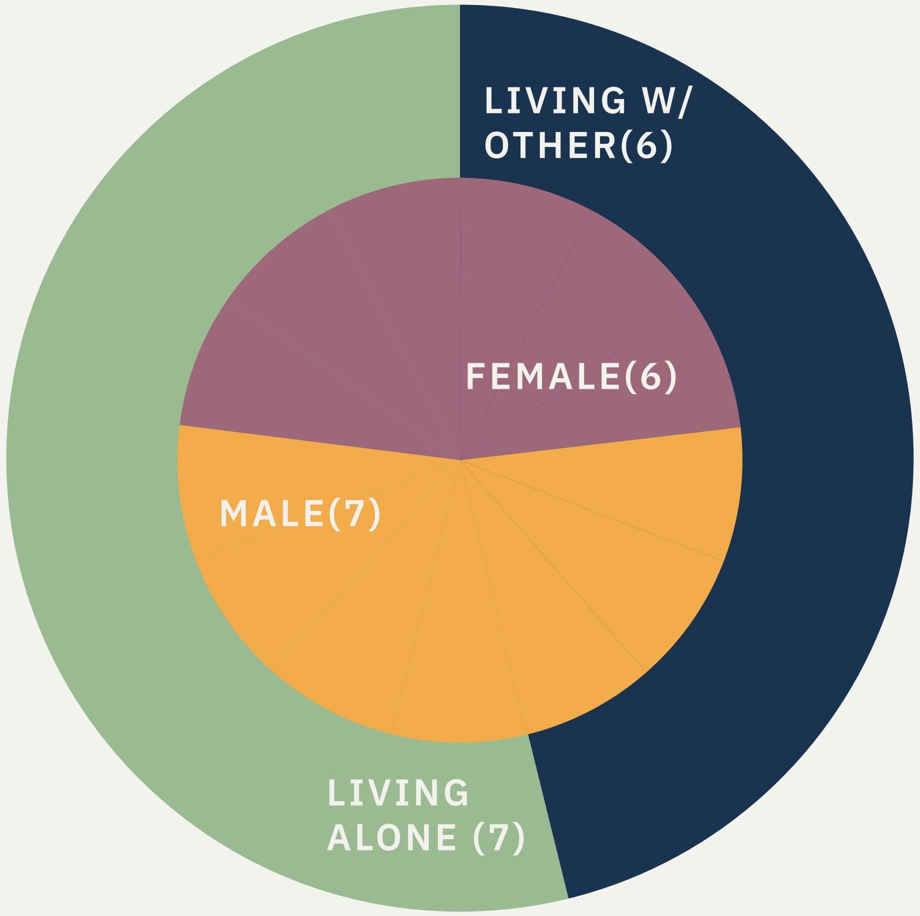
We originally targeted a user group that was representative of the general population in Tower Hamlets, considering race, ethnicity, and type of care received, among others.

Though we weren't able to connect with someone from the Vietnamese/Chinese cohort, we believe we captured a fairly representative sample of voices, points of view and experiences from the borough.



3S | THREE SISTERS
A | APASEN
D | DIVERSITY
E | EXCELCARE
CSB | CARE SOLUTION BUREAU

WB | WHITE BRITISH
B | BANGLADESHI / BRITISH BANGLADESHI
AC | AFRO-CARRIBEAN
WO | WHITE OTHER / EUROPEAN
S | SOMALI



This chart shows also the relationship between those males living alone (4), versus males living with others (3), and so on.

Since 2015 you've been bed bound?

“Yeah.”

And how has your care changed over that time? The care that you're receiving and support?

“The same, I think. Yeah.”

So you haven't found much change over that time?

“No. Afterall, I don't go anywhere, so there’s no change.”

INTERVIEW #1
DOMICILIARY CARE USER

DESIRED EXPERIENCE

As one commissioner shared, around ‘80% of all of our acute care costs can be accounted for by roughly 20% of the population’. The Pareto Principle. We believe in this principle, and that transformative change can come by facilitating incremental, 5, 10 and 20% adjustments. ‘Bucky’ Fuller called this the ‘trim tab principle’.

We think of an experience over time. People and their needs and emotions are non-static, evolving and dynamic, therefore, we present here elements of the current and desired experience that we understood from people in a dynamic way over time.

Also, we have segmented the experiences across four users - as the quote overleaf form one of our discussions expresses - to explore how different types of services can think about different types of experiences.

By better understanding this reality, we can start to imagine those 5, 10 and 20% adjustments that can drive meaningful change.

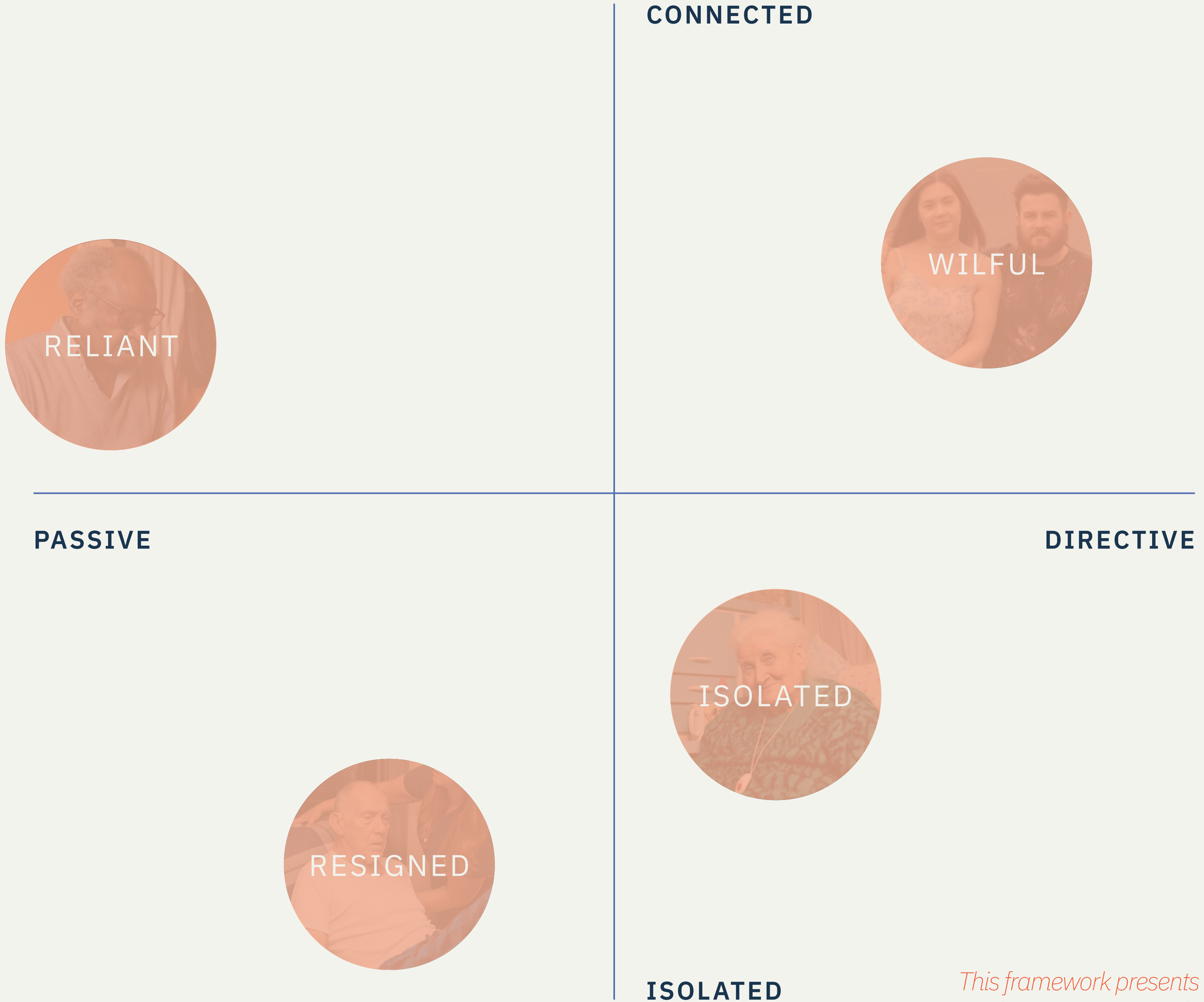
> *“Maybe it's about different cohorts of patients have different things, you know, they'd be stupid just give everyone the same thing. You know a young disabled person whose physical immobility makes it difficult for them to get out of a house versus someone who's 85 who's got comorbidities and is at the end of their life.”*
>
> ***HEALTH & SOCIAL CARE PROFESSIONAL***
> *TOWER HAMLETS*

OUR USER TYPES

Context is everything.

Segmentation provides a framework for us to think more effectively about the type of people we are serving. Importantly, it reminds us that we are not describing a homogenous conglomerate of 'users', but rather, we are working across a broad range of needs, experiences and potential offerings that can respond well to a specific context.

At the same time, these personas remind us that we are working within a specific macro realm - that this is collectively a group with complex, long-term needs, and that this cohort requires a different approach and a different way of thinking, compared to the rest of the population.



CONNECTED

PASSIVE

DIRECTIVE

ISOLATED

This framework presents our four user groups in four quadrants - the quadrants give us a sense of what defines our users, and also provides a sense of where a desired experience could move them.

RELIANT

This person and their family follows without any particular point of view about what they may or may not want, potentially not sure that they have needs worth communicating. They seem to have a dependance on or trust in someone or something - on god, on those around them, on the system, and an acceptance of that in some way.

Ideal reality *

"You know, it's about the simple little things like having a wash that they can do for you to help you... simple things like they wash up that I can't do. I can't stand up for a long period of time, wash up and things like that."

The opportunity

How might we facilitate users early on in their care journey to start to identify goals and a vision for themselves and their care?

How might we develop a capacity of problem solving in the current system - utilizing the trusted agile person to help our users address a range of life and health issues?

I need psychological and emotional support to help me build healthy habits. I have received tokenistic support and engagement for complex issues like my relationship to food.

Because every other day I'm cheating with the diabetes. Which is silly, but thank god it's been on an even keel, and it was good this morning, only 7.5, which is very good, but I spoil myself nearly every day, which is silly.

Yeah, I eat sweet things that I shouldn't eat. The depression gives me a sweet tooth, but I just got to have will power, and I haven't got very much will power at the moment, cause I got a bad cold, and I'm just so badly run down.

I take it out on myself, which is silly...

Because I know the consequences, what can happen. I mean, my father was also diabetic. Before he died he lost both of his legs. He wasn't looking after himself, and he went blind, so my eyesight is not that good.

... Have you spoken to anyone about the diet?

I have, a few years ago – the doctors, they gave me a diet sheet, but I just didn't take notice of it properly. #10

I don't know what to expect nor do I have a strong opinion about my health and my care. I'm allowing the good grace of those around me to take care of it.

What is the social worker there for? What is your feeling about her role?

Well her role, basically, is just to see... what's the word, basically to kind of care, like make sure mum gets the care she needs and support, basically.

Have you had to reach out to her at all since Mom left?

No, no...

Do you feel like you've needed to at all or that you've wanted to?

No, not really. Not really, because as I said, the carers come and do what they're supposed to do, and so there's no need really. #6

And how is that process for you, transition to this kind of new setup and new support?

Um, it was OK, it was fine, it was OK. I never had any issues or problems with it – it's fine. They just come in and do what they have to do, and I do what I've got to do, so, yeah, it's fine. #6

*****

Are there things that you guys are working towards for your health and mobility?

Not really, they haven't really mentioned it now.

Because obviously, being the way she has been for so long, obviously, her strength might not be as strong as it used to be... and the balance as well. They haven't said anything, so I don't know. #6

I don't take my care for granted. The things I'm being supported with are basic day-to-day tasks, which has a huge value.

The carers, they come here, make sure I got something to eat, and then they go, because they got other people to go look.

So how long are the carers here for?

10-15 minutes.

Even the neighbour next door tells me how good these carers is... wash my clothes, all kind of something to do. I don't think they need to do them things, but they do them.

So there's some things you don't think they need to do, but they do them anyways?

Yeah, they sweep there, and the kitchen, take the rubbish down – all them things they do. I got no complaints about them. #11

*****

It's a lot of help... probably won't be able to do things like wash my hair, clean me legs and things like that she does for me. You know, it's about the simple little things like having a wash that they can do for you to help you... simple things like they wash up that I can't do. I can't stand up for a long period of time, wash up and things like that. I can't hoover anymore, because it all hurts your back. People don't realise when you got a back injury, it hurts. #3

I struggle to maintain an understanding of what's going on with my health and the system around me, and especially the information I'm receiving about it. I tend to rely on ask the person I am most comfortable with.

How often would she see the doctor before going into the hospital (8 months prior)?

Touch wood, thank god, she was actually quite a healthy person you know, it's just recently all this started.

How long has your mum had diabetes?

November. She might have had it before, but she didn't know.

OK, so this is all very new.

Yeah, as I said, she might have had it before, but she didn't know. It's only when she went in hospital and they tested. #6

*****

So with this letter from the local authority [about the cost of your care] you'll speak to them at [the community mental health team]?

Yeah I'll speak to [my nurse] and ask her what's happening.

Is that who you feel most comfortable to speak to about things – [your CMHT nurse]?

Yeah, cause she sorts things out for me. Because I can't understand what they're trying to say to me. #3

RESIGNED

This person has accepted something unpleasant that he/she cannot do anything about. He or she is in a long-suffering state where they have become tolerant of their care and their current physical and mental state.

They have decided to stop communicating, and in fact, don't see much value in it.

Their ideal reality

"Years ago, I used to have a carer... come from a different [care agency]. And she used to come and she didn't need to do anything, just sit there for an hour or so and talk with me.

...she come and talk to me – no other carers do. I thought it was quite nice, because she spent the time, even though she didn't have any physical thing to do..."

The opportunity

How might we create opportunities where carers just listens and understands?

How might we continue to imrpove communication across care providers to increase trust?

I need a human being - a warmth in relationship. I don't have this.

To hear and be heard is connection, it's also building trust in a system that hasn't worked for me in some time.

• I fall down and I twist on my back, and I broke [my ankle]. So actually, all this section of the leg... put together. And then [my social worker] arranged some people, it's not like she was a social worker, she was a human being.

I didn't have this phone you know that – land line, but I had the mobile anyway. I begged them, she rang them up, and I had the telephone line. And she would ring me up every day... 'how you doing?' 'Oh, I'm doing all right'. #8

*****

What's your relationship like with these 10 or 11 people? How would you generally describe your relationship with them?

There is no real relationship. Just come and do their job, and then go, as quickly as possible. Yeah, they don't stop and chat.

Years ago, I used to have a carer... come from a different [care agency]. And she used to come and she didn't need to do anything, just sit there for an hour or so and talk with me.

Why do you remember that particular carer, why was that meaningful?

Cause she come and talk to me – no other carers do. I thought it was quite nice, because she spent the time, even though she didn't have any physical thing to do. #1

In fact, regarding my GP, I'm feeling indignant, and even indifferent.

The GP feels distant / removed from my health concerns, and I don't trust they can serve me effectively.

What's your relationship with your GP?

Haha, what relationship? I don't have a GP, it's the GP practice. One of the people turns up occasionally. Not very often.

I've never been to the surgery. It's somewhere over there.

Do you know the name?

The word 'green' comes to mind... #1

Yeah from the GP, for 9 months I call every single day, every cream I have here. Nothing that works

They never help me to find out how to get that one. They give me something else.

Did they not understand it was bed bugs?

[family member]: Maybe they don't. I don't know what they understood but they weren't doing nothing about it. #13

I accept my care as it is because I think I have to and I don't know how to exercise control over it. One worry is that I may lose it. I feel resentful.

So do you have any choice in that? Have you expressed that concern to [your care provider]?

Do I have any choice? Of course everybody has choice. It was either cancel the whole shebang, or just shut the fuck up and put up with it.

So you feel like you have to just put up with it?

That's way I felt, at that time. Because they're not doing their job, but a bad hand is better than no hand as far as I can say it. If there's no one there to give me a hand.

Do you feel reluctant then to speak out for yourself because you're worried...

Well, of course, because if I get rid of them, who is there? No one is there. It's going to take me a hell of a long time to get somebody. I'd rather have somebody bad...

I've seen situations like that, because one of my friends was living in Poplar years ago. There was people working for him, you know, helping him. He got rid of them and it took him years and years and years to get back that credibility for them to send somebody else. #8

I've learned that people don't listen. When things go wrong, I will wait for them to get worse before someone acts.

My main concern is no money and no food. The bank. That's the only thing I need to get sorted. I can't call them because the phone's not there.

How pressing is the issue?

Very.

If you have a pressing issue like that how are you able to communicate the urgency of it to [your social worker] or to the carers?

They'll notice, because they know there's no food. Or they'll say, you only have food for two days. And that's it. #1

WILLFUL

There's a stubborness and determination to get what one wants with this user. Whether it is this person, or someone from their family, they openly communicate needs and aren't afraid to say 'no, you're not doing a good job'. Being able to dictate the conditions of their care in service of self-care and autonomy is fundamental.

Their ideal reality

I need rituals and rhythms to give the day more progress and meaning - that's dependant upon the timing, structure and discipline of the nurses and carers. In this case, meaning is building a greater sense of independence - to 'be the woman I used to be.'

The opportunity

What is the opportunity for this group to contribute to wider support in the community? How might we catalyse this group to support others?

How might we support rituals and rhythms in the lives of our users to build greater structure, discipline and routine?

Control over my day-to-day routine is a means by which I access independence. Without the choice, I'm left feeling frustrated and disappointed.

Often this is dependant upon coordination between nurses and carers.

- I'm so used to getting up at half 6 in the morning, going into work by 8:00, 8:15 and starting a day, and I think I need that... sort of a little bit of structure. Otherwise I'm sort of, you know... like today, for example, the district nurse was late, so now it's two o'clock and I haven't done anything, other than at a quarter to seven this morning, I had a shower, washed my hair. And that was it. You know and I sort of think, ughh. And then by the time it gets to four I think, tomorrow. And every day is tomorrow sort of thing. #4

*****

Oh, yeah, they're good. I'm not a machine, or I'm not a cat. You can't just leave food and go away. Like when I'm hungry at different times... Do you see what I mean? #9

I'm clamoring for independence and old parts of my life (work, habits, etc.) that represent autonomy.

I'm marking it out now, and I'm going to cut a square out and put another square in...

So it sounds like you used to do quite a bit with tools...

[family member]: Mm, he used to be a carpenter, he used to be a builder. So, he thinks he can still do that sort of stuff. We keep telling him...

So it sounds like there are some things around the house that used to be important. You're still trying to take care of things.

Still think I can still do it, but I...

[wife]: He can't do it basically.

How do you feel, because you know obviously that your body is...

Very degrading. Keep telling me, you can't do it, you aint doing it. #12

Meeting my needs is in line with supporting autonomy.

Tower Hamlets needs to look at these pullups for disabled people. Why are they only allowing two a day? Like, that's disgusting. In my eyes it's disgusting, two a day. And they know some people have four a day, six a day. You know what I mean? And I think that's where [he's] getting all these water infections from in his urine, because where he's sitting in the pads, and he's obviously frightened to change them, because we've got to go out and buy them. Like twelve weeks eight packets, and he can use a packet in a week.

What did your doctor say...

They've all tried, even the district nurse, she come around to me last Friday, she said, 'I've been in touch with the Mile End Hospital who issues them, and they turned around and said, no.' All they're allowed is two of them, but the other ones he can have as many as he wants. Well, they're no good, so we might as well stay with what he's got. #12

I can see how I've learned/ am learning through adversity. I'm building independence and know-how by scrutinising the details of my care, often due to a lack of trust in clinical expertise and true concern for me.

That time it was the urine, so that time the care just stopped. I had no sores, but I think the urine infection I had. At that time, it was still all new, I didn't know temperature, I didn't know feeling thirsty, I didn't know the signs.

Yeah, trial and error. So I've really been through it all now, so now we know how to help ourselves.

...I think they're busy, they're not bothered, they're just doing their job. It's not all of them, but most of thersm. So 7 out of 10. So I'm just doing it for the sake of doing it. And the other three are basically doing it and keeping us alive, because they genuinely care. #9

Quality is the extra inch. I'm paying attention to the details of care.

- I think attaching a sling to the hoist is something that they're very fastidious about and they seem to double check, make sure I'm in it correctly before they go, and I'm sure all of them check, but some of them don't seem to check as thoroughly. Little things that some of the carers might not notice is that there is a load of dry laundry hanging up somewhere and I always think, a good carer would say, 'oh they're dry, I'll tidy them up and put them in the cupboard, and somebody who doesn't see it... it's not that they're a bad carer. They can transfer me and they're competent, but they just wouldn't go that... It's not even an extra mile, it's an extra inch. #4

...It's not that they're doing something wrong, it's just they're not doing something, or not seeing it. #4

I am working directly with my carers and my care agency to mold my plan and package as we go - so much so that I'm even informing operations and hiring decisions.

You said that you're quite vocal, and you said that you're willing to express when you're not satisfied. Who do you communicate that to?

With the carers really. I don't have much contact with the agency, cause I've got no issues, no complaints and if I do I just tell the carer. But if I do have complaints, there is... so I've got 2 numbers for the care agency where I can speak to them directly. #9

*****

And then there's another carer that I had that used to work with me quite a while back. I've asked her to come on and so hopefully, they said she can apply, and then they'll just keep an eye out for her application. She worked with me quite a while back. She's quite good, and we've stayed in contact. I literally just spoke with [the agency] about that a couple of hours ago. #9

I want my carers and nurses to work to the standards that I would work. I have expectations about how things should be done.

You use a face [towel] once, you wash it. Use a towel you washed him in the shower – dried, that's dirty. In my eyes that towels dirty... no, he hangs the towel over the edge of the bed. He can use that tomorrow, I went, 'no, it's dirty. He's used it once, that is it...'

OK, so what I'm hearing then is that you've told him that you want things done a certain way around hygiene and cleaning...

Yeah, obviously that's my... it's the way I grew up. #12

ISOLATED

Either because of language, mental health, mobility and/or disposition, this group is at a distance from the person who can support them with their needs.

Ideal reality

I need someone who trully represents and communicates my interests and needs.

They are good to me. I have a friendship with them, and I like to chat with them too. There are so many things we talk about – cooking, life stories and domestic life. #2

fresh weather is important part of life. #7

The opportunity

How might we support greater independence and reduce fragility for those with language barriers, particularly for more vital conversations?

How might we build opportunities for unstructured time for basic daily activities (walks, talks, bills, etc.)?

I may have family around, but I can't rely on them for much support.

How does your mum feel about...

She is already sick. She got diabetes and (high blood) pressure and so many problem...

And when she has to help you, how does she feel about it?

Hard for her because she is about 84, so hard for her sometimes. #5

I'm not sure how to address a range of issues (health and non-health). I think alot about them and it causes me anxiety.

Then I'm joining them, I'm feeling relaxed, so I understand my daughter is here, my son is here.

So you would feel like you can relax?

More, yeah. Now I suppose carer gone, you gone, after one by one cigarette.

Do you find you smoke more when you're by yourself?

Yeah, alone, because thinking coming.

Thinking – you find that when you're by yourself, you're thinking a lot?

No, not that. Thinking suppose everything – thinking, where is my son? Where is my daughter? How their position now? Plus, this house's problem – leaking, broken, plus they told me to apply to the council, and tell them wheelchair, you'll need a big flat, big door... #7

I can communicate directly to my carer, but often they're the only person who can communicate my needs on my behalf, and at times crucial things like safeguarding issues (which could potentially be a conflict of interests).

Who helps you communicate that need to [your carer's] and other people outside of the house?

I do not have anyone.

For example, if you need to make a doctor appointment, who can help you do that?

No one helps me, so I rely on the receptionists to speak Bengali.

Do you do it on your own or does your carer help you?

My carers help me... Doctor appointments and sometimes with my bills. #2

*****

Last time asking I need, suppose tomorrow, I'm going to my kid's house, my daughter's house. So after Eid tomorrow then 3 days after I'll be back, so these three days, I don't need, I don't want service, because my kids, they'll look after me. So again, I tell them Monday morning to start again. #7

Even the English that I do know is not well understood by others.

So like my food, sometimes he is not giving delivery so I call, but my speak, these people sometimes not understand me. Carer is okay. Because he is Bengali.

Okay, do you find it easier to speak in Bengali?

Yeah. Because sometimes my voice people not understand. So like, my voice don't come properly.

Okay so it doesn't come properly. Are there times when he says 'I don't understand you,' does he say that to you?

Sometimes people say. Not understand proper. #5

ACROSS USERS

These are a collection of hypotheses that we felt were most relevant, and do not necessarily fit snuggly with any one of the 4 user profiles in this section. Each user type will have a different response to these based on what we've described in the connected | directive framework.

Ideal reality | validation and connection

"Years ago, I used to have a carer... come from a different [care agency]. And she used to come and she didn't need to do anything, just sit there for an hour or so and talk with me.

...she come and talk to me – no other carers do. I thought it was quite nice, because she spent the time, even though she didn't have any physical thing to do..."

The opportunity

How might we adapt the creation of the care plan out of hospital, so people are able to meaningfully collaborate on it once they are better?

More intensive care is a long time coming - there is a transition time to more greater dependence on care.

I've got multiple sclerosis and I've been in the wheelchair for many years and I've had care probably for the last 12 years and used to have care in the morning so that I didn't tire myself out before going to work and for safety... I was rushed into hospital and that was October of the year before last. As a result I've had to give up work... I had worked with my M.S. for twenty-three years.

...I was diagnosed about 26 years ago or something like that. And I was okay for the first sort of six or seven years, and then it started affecting my mobility. #4

Getting outside regularly is a lifeline.

How are you feeling about being able to go outside more regularly?

Better... fresh weather is important part of life. #7

I need someone who can help me problem solve, and complete challenges.

What do you want for you wife and your son?

I want to bring them here, because I can't go by plane because I got another stroke maybe I dead. So I can't go... it's so hard... I don't know how to bring them here.

...it's a long time now before I go. I come in 1976 to this country. I going Bangladesh about 3-4 times. Last time just gone in 95, I'm not going back, 2009. 2019. No, 1999.

1999, that was the last time you went?

Yeah.

People are living on a shoe string - every little bit is important. This is true across all users.

- So the problem is money sometimes – end of month all payments coming due that day, from the beginning to that day. Half week is ok, half week is crisis. #7

Relationship - time to speak and listen is the most important task.

What's your relationship like with these 10 or 11 people? How would you generally describe your relationship with them?

There is no real relationship. Just come and do their job, and then go, as quickly as possible. Yeah, they don't stop and chat.

Years ago, I used to have a carer... come from a different [care agency]. And she used to come and she didn't need to do anything, just sit there for an hour or so and talk with me.

Why do you remember that particular carer, why was that meaningful?

Cause she come and talk to me – no other carers do. I thought it was quite nice, because she spent the time, even though she didn't have any physical thing to do. #1

Assume that I can't see nor read - either my vision has deteriorated at such a pace, and/or I simply can't take in the information you've sent me in written form for a number of reasons.

Actually, when it started, I can't see properly

You can't see properly?

Yeah... sometimes, too much dizzy, I can't see properly. #5

There was a lack of communication about an issue I had, people weren't speaking across services. A lag in proper and vital treatment ensued.

She used to get people from the hospital coming – physiotherapist... They wasn't told, and I wasn't told either that she wasn't supposed to put pressure on that right foot, cause it still had the sore in it, it was still in the healing process. So obviously putting pressure on it, it will just make it worse again, so they stopped coming after that because she couldn't do it...

You said that they didn't really tell you that she needed to keep the sore untouched right. So how did you get all that information? Did that come when you left the hospital. Who is communicating all these things?

No, that was the nurse, the nurse was saying we shouldn't really put pressure on it... I said to the physiotherapist... I think when they went back, they started communicating with one another... the nurse said to the physio, she's not meant to put pressure on it. So the chiropodist come one day and gave her the boot to keep the pressure off of that heel. #6

Carers are at times cutting corners and trying to do far less than is expected, at times even putting the user in danger.

And then I come home from work one day, it was early. And they was supposed to be here 9 till 12, and this is about quarter to 11. And he's standing at the bus stop. And I come in, I thought to myself, why is he at the bus stop, he's supposed to be there 'till 12?

So I come in, he said, yeah, he's just gone. Well, he shouldn't, he should be here for another hour and 15 minutes. Then he's seen me coming in and he's come back, 'I'm sorry, I'm sorry'. I said, 'well, why are you [ ]? You doing this every day? Are you leaving him every day?' 'No, no, no, no, no.' I said, 'but why are you doing it now?'. 'I come back. I don't want you to report me'. 'Well,' I said, 'I'm going to report you, because that hour and a half, he could have had an accident and there's nobody here'. #12

I appreciate my relationship with my carers - we connect and share on a range of things.

What do you think of your relationship with your carers?

My relationship is good, and they are good to me. I have a friendship with them, and I like to chat with them too. There are so many things we talk about – cooking, life stories and domestic life. #2

Coming out of hospital people can be so fatigued and weak that they are unable to engage in a meaningful discussion about their care - in some cases it's dictated for them.

How about a care plan? Is there a care plan for you?

Yeah, and everyone knows what they're here to do within the time slot that they're coming, and I know what to expect, so yeah, that's...

How was that particular plan developed?

I think probably my social worker and the occupational health who stepped in when I was admitted to hospital and was so very unwell from the pressure sore, so they did it. And in discussion with me. But I knew what I needed, which was a lot of help, because I had come home from hospital, but I was so weak. #4

05 | INSIGHTS

OUR KEY INSIGHTS

After developing and exploring the sum of our hypotheses, presented in the Apendix, we synthesised, or blended, these main insights.

The insights are not recommendations, but they provide a steer for what we believe to be the main opportunities to understand and improve the user experience.

Now that you've gotten a sense for what the user experience feels and looks like more granularly, we present these 5 insights

a hierarchy of needs

From physiological care to belonging and affection, we present the things users find meaningful in their lives.

storytelling for complexity

Declining cognitive and physical capacity coupled with change, chaos and embedded systems within systems demands better navigation.

a balance of push & pull

The necessary harmony required for users, carers and nurses to hold the tension between affection and non-attachment.

relating to my care package

From the moment of creation to the first review and beyond - we are thinking about how the life cycle of the care package can better serve the commissioning priorities.

the need for problem solvers

Perhaps more than anything, along the hierarchy of needs, users are sensing who they trust the most to help them solve issues from housing to health to money.

quality | the extra inch

A HIERARCHY OF NEEDS

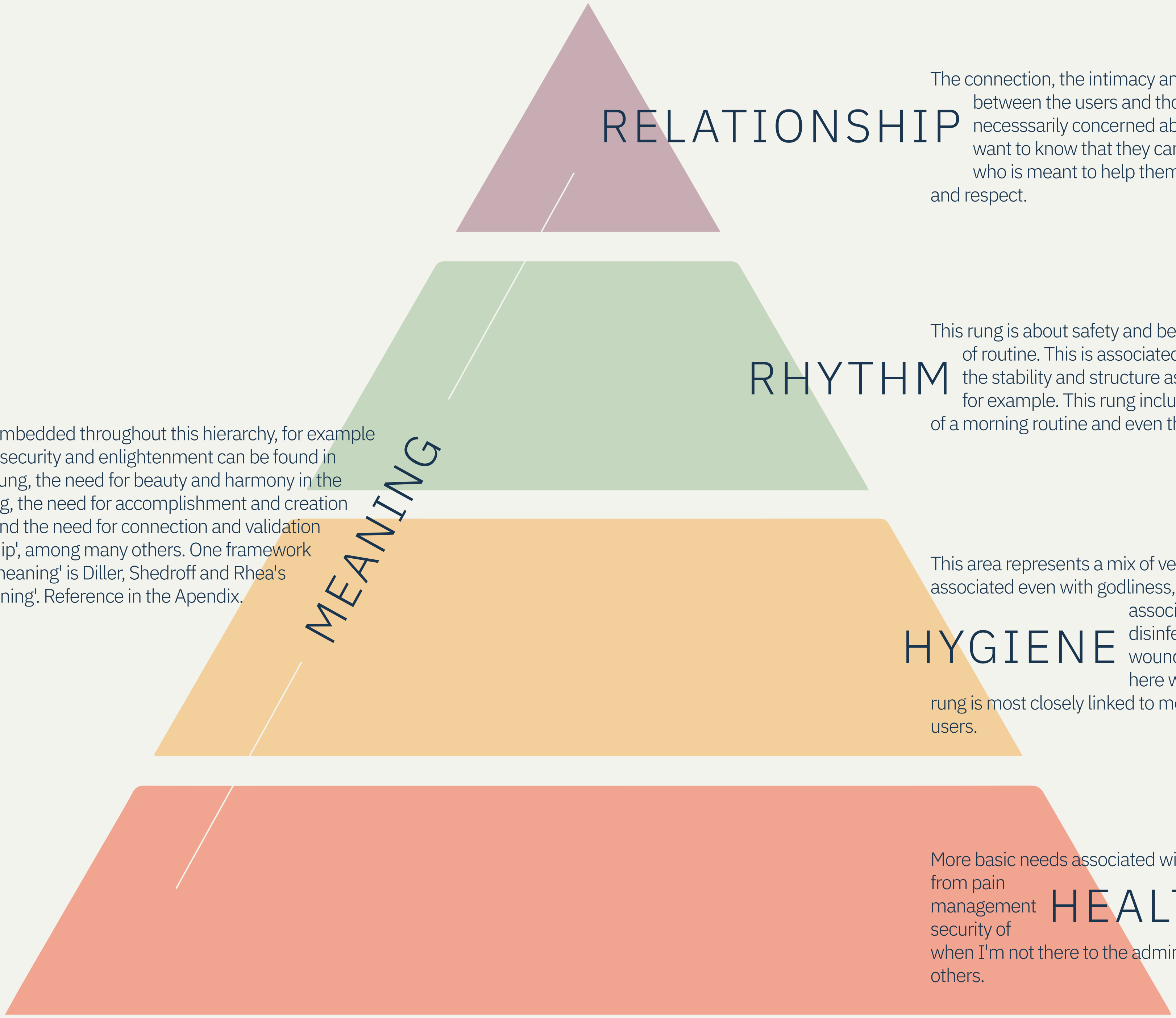
This hierarchy of priorities is a depiction of what we heard and understood from the point of view of the user.

Users do not split tasks into ‘health’ and ‘social’ – they are more concerned that their carers and nurses address a range of issues along a hierarchy of meaning, if you will. In fact, throughout the interviews, they’ve described carers and nurses participating in each level across a range of functions.

The bottom, or the root, denotes crucial, physiological needs, similar to the ground of Maslow's hierarchy. As you move up, you find safety, belonging and love and respect.

So we are posing the design question:

How might care better support the users connection to meaning?



The connection, the intimacy and the perceived care and affection between the users and those in their home. People are not necesssarily concerned about the task, so much as they want to know that they can trust and confide in the person who is meant to help them - it's a desire for esteem, dignity and respect.

This rung is about safety and belonging - about the predictability of routine. This is associated, potentially with order and even the stability and structure associatd with having a full time job, for example. This rung includes the ritual of church, the hum of a morning routine and even the predictability of their care.

Meaning is embedded throughout this hierarchy, for example the need for security and enlightenment can be found in the 'health' rung, the need for beauty and harmony in the 'hygiene' rung, the need for accomplishment and creation in 'rhythm', and the need for connection and validation in 'relationship', among many others. One framework we use for 'meaning' is Diller, Shedroff and Rhea's 'Making Meaning'. Reference in the Apendix.

This area represents a mix of very crucial cleanliness, at times associated even with godliness, to a more psychological need associated with expectations of basic disinfection. Even hygiene around wound and health care could overlap here with the bottom 'health' rung. This rung is most closely linked to met and unmet expectations from users.

More basic needs associated with my wellness - everything
from pain to my nutrition and the
management of my diabetes to the
security of my demented husband
when I'm not there to the administering of my insulin, among
others.

A HIERARCHY OF NEEDS

For each section of the hierarchy, we've presented here an example of a met and unmet need.

A more exhaustive list of examples is presented in the appendix.

unmet need

I need another house, because this flat is very old. My daughter she joined me already in this flat. She live with here, not regularly, because the [indiscernible] no good, plus problem in this room [indiscernible] very small, so I need two, three bedroom house – I want if it is arrangement for housing people to talk to you, then in future my daughter and my son, school teacher, and my daughter, they are buying... They'll look after me. They'll look after me. #7

What's your relationship like with these 10 or 11 people? How would you generally describe your relationship with them?

There is no real relationship. Just come and do their job, and then go, as quickly as possible... they don't stop and chat.

Years ago, I used to have a carer... come from a different [care agency]. And she used to come and she didn't need to do anything, just sit there for an hour or so and talk with me... I thought it was quite nice, because she spent the time, even though she didn't have any physical thing to do.... #1

I'm so used to getting up at half 6 in the morning, going get into work by 8:00, 8:15 and starting a day, and I think I need that... sort of a little bit of structure. Otherwise I'm sort of, you know... like today, for example, the district nurse was late, so now it's two o'clock and I haven't done anything, other than at a quarter to seven this morning, I had a shower, washed my hair. And that was it. You know and I sort of think, ughh. And then by the time it gets to four I think, tomorrow. And every day is tomorrow sort of thing. #4

Somebody who can do their job... he's doing one, two, three, four hours a week, and my house looks like that. And it's only this little room.

How do you get a sense of how the house is. How can you sense if it's clean or not?.. you said for example that the carer doesn't do a very good job because he's kind of...

I can feel it. You know if you go like something like that (swiping his finger on his bed side table). And you go like that, you can tell whether it's been clean or not. Oh come on, I may be blind, but at least, I know when something is clean or not. #8

And then I come home from work one day, it was early. And [the carer] was supposed to be here 9 till 12, and this is about quarter to 11. And he's standing at the bus stop. And I come in, I thought to myself, why is he at the bus stop, he's supposed to be there 'till 12?

So I come in, [He] said, yeah, he's just gone. Well, he shouldn't, he should be here for another hour and 15 minutes... 'Well,' I said, 'I'm going to report you, because that hour and a half, he could have had an accident and there's nobody here'. #12

met need

What are some specific things that happen on a good day?

I feel better when my carers take me outside... I feel better when I go out. I get to speak to other people too... I like to be in nature. #2

The carer. Yeah. I said if I didn't have her help, I don't think I'd be alive today, because she looks after me... As soon as she comes in, I mean she mops every day, she washes up, she won't let me do my own breakfast, she spoils me... she does everything. When she sees I'm a bit sad, she gives me a hug. She's loves me. I'm like a mother to her. And she's such a lovely woman...

Yeah, [my carer's] absolutely a diamond, if I didn't have her coming here, I wouldn't have no life. I wouldn't be able to cope. #10

Well I used to drink, smoke, all kind of things that was bad... womanise. Since I accept Christ, I live a Christian life.

...help you to live a decent and Christian life. That's what the church does. It's really good to me. It helps me a lot... even with my sickness. [ ] prayed for me, and all that and help me to where I am now... because when you're a Christian, you don't do things that you normally would do, like gambling and things like that, you just live a Christian life and live Christ alone. #11

Because if you don't have that help, you're going to be like smelly, you won't be able to do things yourself. It's a lot of help... probably won't be able to do things like wash my hair, clean me legs and things like that she does for me. You know, it's about the simple little things like having a wash that they can do for you to help you... simple things like they wash up that I can't do. I can't stand up for a long period of time, wash up and things like that. I can't hoover anymore, because it all hurts your back. #3

So after, there was a nurse that came the other day, she's a new nurse. It's not like she's going to come back here, but she said, 'just in case I come back, how do we do your legs again?'. 'Oh, calm down', because I couldn't breathe properly. She said 'Don't worry. Don't worry. Take your time.' And then she's looking for the spray – she's like, 'do you have [ ]', just for extra protection. She's taking her time, she's looking at the wound, she's pressing it, and then she's dusting off my bed, and I thought, Wow! It's not like she's a new nurse and she's going to see me all the time. She was just here on site just to cover, but her nursing was very good. And I told everybody about it as well. #9

“So the nurse comes every day to give you the tablets. What are the tablets for?

Oh it’s diabetics… it’s what they call like a blister pack. ***I've got the faintest idea*** *what the heck… because I got diabetes. I’m supposed to have high blood pressure, which I’ve not been tested lately… Look,* ***I need MOT. If I was an old car, I’d be brought down to the scrap.”***

INTERVIEW #8
DOMICILIARY CARE USER

STORYTELLING FOR COMPLEXITY

The MOT for #8 is a one stop shop. It's a single place where he can easily navigate the complexities of his health, his drinking challenges, his pain and the vastness of the health and social care system.

Here, we are highlighting the elements of the user experience that make complexity a mainstay of the user's day - a level of complexity we don't see decreasing over time.

One key way cultures, groups and societies have been able to navigate chaos, change, and the challenges of nature is through storytelling. Relaying values, wisdom, practical knowledge and know-how in captivating ways has built resilience and antifragility into humanity for millions of years.

So we are posing the design question:

How might we better employ storytelling to build resilience and awareness and help users of health and social care navigate the complexities of the day-to-day?

Increasing complexity

- Change
  - processes (in the system)
  - cycles (new carers, GPs, etc.)
  - benefits
  - chaos/ sudden, drastic
    - Covid, etc.
- Insight
  - Expectations (e.g., what is quality?)
    - What do I demand?
  - roles & responsibilities
    - Who do I speak to for what?
  - Managing my conditions (how to)
  - Understanding why (why this treatment, etc.)
- + Cognitive decline
  - ageing
  - stress
  - disease (dementia, etc.)
  - depression \ mental health
- Immobility
- Isolation
  - reduced community assets
    - My community centre closed - where I had my eyes checked.
  - bereavement \ loss
- Language
  - validation (e.g., saying what I need)
  - dyslexia
  - blindness / eyesight
  - comprehension (ESL, vocabulary, etc.)

WHAT COMPLEXITY LOOKS LIKE

understanding why

I go crazy sometimes you know, I can't go anywhere. She's over there, I feel like a yo-yo you know? What can I do?

You feel like a yo-yo? Why is that?

I can't understand why I have this [catheter].

It's frustrating when you don't understand fully what's happening.

All the time the appointment is cancel. I can't believe this. When I go to the hospital, I complain to the doctor and they said to me that 'no, you have to stay in the hospital to check properly, stay in the hospital 2-3 days'. And I said I want to go home, I don't want to stay here, what am I going to do here? He doesn't do nothing, he said he was going to check me, but he never touch me. I can't understand to stay over there in the hospital... And they say you want to go home, then I send you home. The next day he send me home the next day.

But he wasn't able to explain to you why you were there?

No. #13

And what's your relationship like with your GP?

process change

It used to be all right. But now you can't phone them up and talk to them, you have to go through e-consultation and you have to fill in all these things before you can get to speak to your doctor or before you can get your medicine. Whereas before you used to be able to phone up your GP and ask them to call you back and speak to him. That's all changed now.

What's your feeling about that?

language

It's a bit long winded just to speak to a GP. And if you're dyslexic, you know, you get confused and that... she phoned me in the end, but I had to do this e-consultation twice to get somewhere.

...I don't know - they sent me a form, but I'm dyslexic and I can't understand it. They give you option things, but I don't understand it. #3

From then on, you know, once you've lost one friend – you get used to one friend telling your problem, and then somebody else take's over, and it starts all over again right. I mean surely there must have been notes that [my old social worker] left behind for him.

Cyclical change

So you've noticed that it's been a difficult transition from [your old social worker] to this new guy?

Well this new guy is more or less asking me, can we start all over again! #8

cyclical change

What else has changed for you during the Coronavirus?

The doctor, I haven't been to my doctor for over a year. They've moved over on Dean Cross Street... Whitechapel, I still don't know where. They don't get in touch with me properly either.

...How would you go about getting a doctor's appointment – you said you'd like to speak to the doctor?

... I don't know cause they moved to Whitechapel... they sent me a paper, but I lost the paper, so I don't even know exactly where the doctor is now. I don't know how I'm going to find out, unless you can find out.

Who would you ask usually? You said you don't know where the doctor is?

I could ask the district nurse who comes tomorrow – they might be able to find out for me if it's possible... I need a proper check-up. #10

Immobility

[family member]: Yeah, it was drastic. He's saying, he can't get out of bed. And that's why I got in touch with the occupational health again and I said to get a bed that sits up like a chair. So she said, 'well, we can try one of the recliner chairs, but the recliner chair only goes back so far. I said, aint you got one that can be used in the bedroom, and use it as a bed? And at least you know he's going to sit up in a sit up position, but they don't do a bed like that.

So your mobility has reduced quite drastically in the last four or five months?

Sudden change

[family member]: Yeah, big time, big time. #12

Managing my conditions

And the routine is very complex – the routine and technique as well, and because it's quite complex. I can't just have a carer take over. If it's just like getting my food ready, or helping me sit up and stuff, it's different. But this is like putting the pillows under my legs, and doing this, and doing that, and getting pressure off my backside. So yeah, it's very complex. #9

Sudden change

So you lost eyesight or your full eyesight around January and then obviously the [virus] hit, so you haven't really had a chance to go to Moorfields [and be checked out] properly. What are the nurses doing or the doctor - you haven't spoken to the doctor about that?

Perceived inaccessibility

My doctors closed up 24/7... might as well break into the Bank of England. #8

WHY STORYTELLING?

+ It potentially shapes **more realistic expectations**.

+ "What people expect from their health care compared with their experiences may influence their satisfaction with it. There is also some evidence that **patients who receive the health care they expect may recover better than patients who do not**."*

+ It provides **visions and goals for potential future states** and guides change for users in the present.

+ It has the potential **to connect their day-to-day experiences more closely to what is meaningful** to them (see figure 4 from Nesta's Good and Bad Help - Appendix, page...), in a similar way to fables, myths and legends.

+ It could offer very practical advice and information **to nagivate the complexity** of the health and social care system, their own mind and bodies, and the general challenges of a quickly changing world.

+ Stories **affirm our experience in the world**, they remind us that we are not alone, and that others have felt and are feeling exactly how we are in the present.

+ Stories can **shape and change our own personal narratives**, for instance, the things we tell ourselves that may be a cause of our poor health.

*https://www.ncbi.nlm.nih.gov/books/NBK99051/

“But I haven’t had a good life, really. I was raped by my own father years ago, which doesn’t help... And I worshiped that person.

It’s made my nerves very bad, because of my own father. I’ll never get over that, I think...”

Have you been able to speak to anyone about that – the abuse?

“I have, yeah, but I haven’t got very far. I don’t need to see a psychiatrist, because with the help from [my carer]...”

INTERVIEW #10
DOMICILIARY CARE USER

A BALANCE OF PUSH & PULL

There is a harmonious balance of light and dark, push and pull and give and take that must exist for people, relationships, ventures, societies to flourish, in the same way a tree stores Co2 only to exhale O2.

People doing their job, and not just doing their job, the tension between an affection and an expertise,

What we heard in the interviews is that users value both sides of this symbol depending on the time of the day, where they're at in their journey and who their carer and/or nurse is.

This is an old design principle - yin and yang, and also a useful place to start when thinking about the necessary balance of components for quality care.

So we are posing the design question:

How might we more harmoniously balance care that is affectionate and direct in order to build resilience and wellbeing in our carers, nurses and users?

How might we more harmoniously balance care that is affectionate and direct in order to build resilience and wellbeing in our carers, nurses and users?

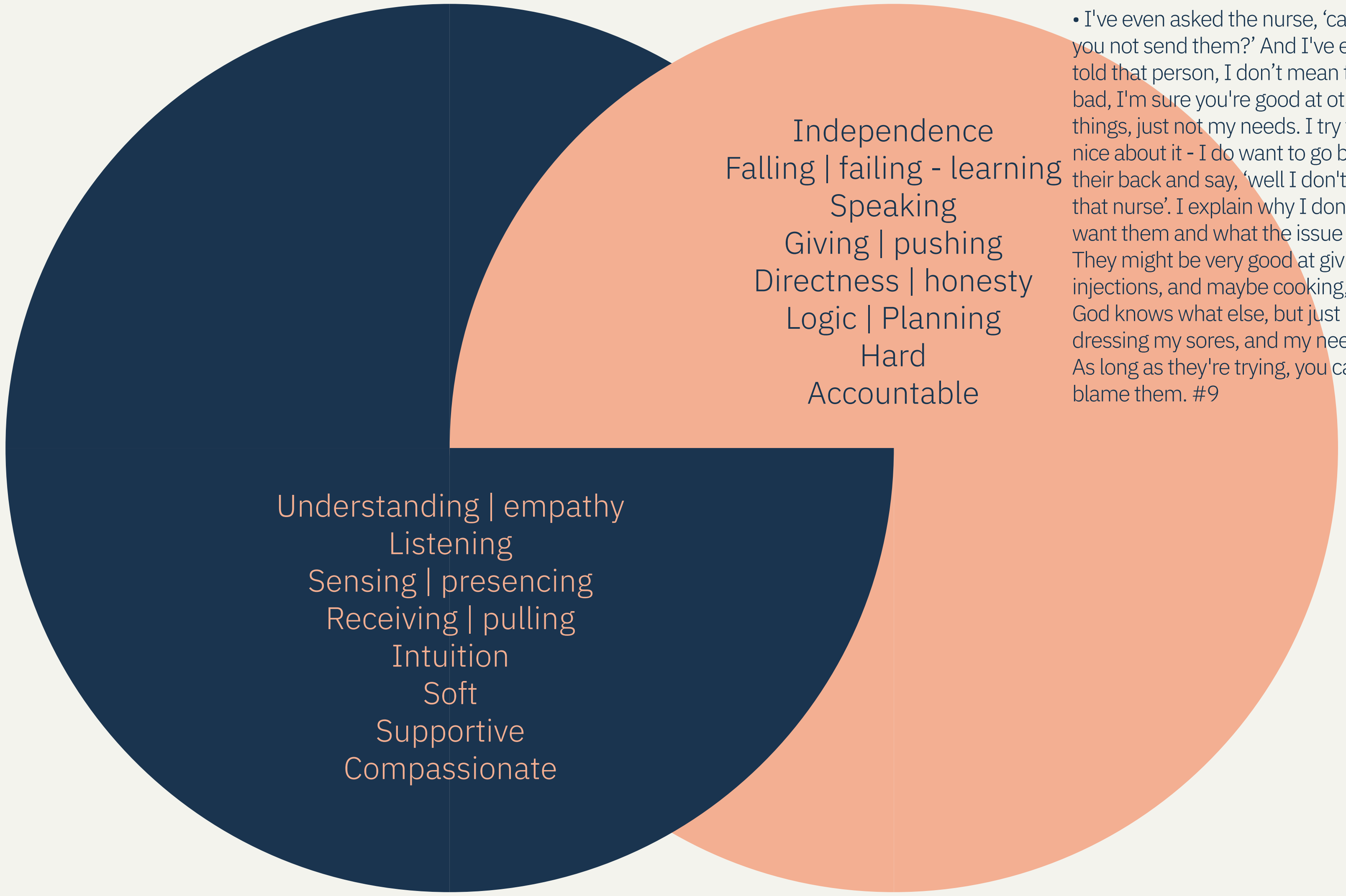
For those who are fragile or vulneralbe, deviation is harm.

The quote on the previous page,

Tension between affection and non-attachment?

Between support and boundaries?

This is contextual based on the person in front of you. How do you adapt that care to hold what the carers need, and what the patient needs?



Independence
Falling | failing - learning
Speaking
Giving | pushing
Directness | honesty
Logic | Planning
Hard
Accountable

Understanding | empathy
Listening
Sensing | presencing
Receiving | pulling
Intuition
Soft
Supportive
Compassionate

- I've even asked the nurse, 'can you not send them?' And I've even told that person, I don't mean to be bad, I'm sure you're good at other things, just not my needs. I try to be nice about it - I do want to go behind their back and say, 'well I don't want that nurse'. I explain why I don't want them and what the issue is. They might be very good at giving injections, and maybe cooking, and God knows what else, but just not dressing my sores, and my needs... As long as they're trying, you can't blame them. #9

A BALANCE OF PUSH & PULL

Receiving | pulling

- I did have a centre I would go to, Bow Haven, but that’s been closed down since the lockdown, it's been closed down. Bow Haven. That might be shutting down due to funding. So that means I will have nowhere to go. #3

Giving | pushing

- From then on, you know, once you’ve lost one friend – you get used to one friend telling your problem, and then somebody else take’s over, and it starts all over again right. I mean surely there must have been notes that [my old social worker] left behind for him.

So you've noticed that it's been a difficult transition from [your old social worker] to this new guy?

Well this new guy is more or less asking me, can we start all over again! #8

... and when you left the hospital, who was the person who organised the care for you?

"I don't know who organised, but I get them from the time I got here. I think they came here and tidied up the place before I even got home. Yeah, so I think the doctor must have organised that, I don't know."

Was there someone who talked to you when you left the hospital who told you you're...

"No, nobody told me that I'm going to have care workers."

So when did you find out?

"As I said, when I got home."

INTERVIEW #11
DOMICILIARY CARE USER

RELATING TO MY CARE PACKAGE

Currently, the sense that we get is that the care package is playing on the 'bottom rungs of the pyramid'.

From the user's voice, the package is a task-centred list that emphasises more clinical and day-to-day routine tasks associated with eating and cleaning.

Though these things done well are important to users, as we've described, there are other more meaningful experiences and details that users are desiring.

It is also, at times, a rapid process that the user is not able to participate in, as with the quote from #11 on the previous page, a collaborative discussion about the package's content and intention may not happen.

So we are posing the design questions:

How might we centre the care package more around what is meaningful to people?

How might we create enough space out the outset to make the care package more collaboratively?

How might we iterate on the care package once it's created?

How do we ensure a more meaningful review process?

assure expectations are set

- Like face [towels], I got about 30 face [towels]. You use a face [towel] once, you wash it. Use a towel you washed #12 in the shower – dried, that's dirty. In my eyes that towels dirty… no, he hangs the towel over the edge of the bed. He can use that tomorrow, I went, 'no, it's dirty. He's used it once, that is it…

Yeah, like I only use a bath towel once. I don't know how many times other people use it. Face [towels], I only use it once. #12

- *OK, so what I'm hearing then is that you've told him that you want things done a certain way around hygiene and cleaning…*

Yeah, obviously that's my… it's the way I grew up. #12

finances are understood

- How much you have to pay versus how much the council has to pay?

That I don't know because… you saying that, I've just got a form… yeah, a booklet, a booklet, I've just received a booklet. I've got to fill out, and it's got something to do with payment. So at the moment there's nothing finalised about it. I don't know, I suppose after that booklet, obviously they will tell me. I've got to fill it out. #6

- Did the social worker at the hospital go over that at all about the schedule and how long the care will last…?

She did mention something like that at some stage, but she didn't exactly say when that will happen. She did mention something that. #6

Based on what we heard - we're thinking about...

what is meaningful is understood

what is an ideal on-boarding/ check-in process?

participation and autonomy built

iteration is built into the process

if we go out and we should find that the service users need increasing services or need a reassessments that basically would be missed by a social worker, then we would liaise with the social worker.
- health and social care professional | Tower Hamlets

not seen as a set of tasks to comlete necessarily, but rather about a set of time to CARE (for self and user).

'why' is explained

the service user may be having the same carer coming into them which they're happy about, and then they change the carers without letting the service users know. The service users complain. We would like to know what it is because obviously the service user is happy with a carer who they've had all along. And if you change that then you need to let them know the reason why it's changed, or you know. As long as the service user is getting a service with four visits and they start only getting two or three visits then we would like to know why the reason for that.
- health and social care professional | Tower Hamlets

A NEED FOR PROBLEM SOLVERS

In this process of speaking to people about their health and social care, we received a call from one of the users we had interviewed.

He was calling to inquire about a letter he had received from the council. The letter was pertaining to the car he used to own, and the parking space he was paying for at one point.

He didn't know what exactly the council wanted or who to talk to about it, so he called me, the person on his mind who he felt some level of trust in, and who he felt was capable of working through this problem with him.

This is not the first time this has happened in the process of an engagement where we were perceived as a capable, trustworthy person in the system.

So why are people doing this? We believe they are looking for solutions and guidance across a range of issues (parking, housing, etc.) in a sea of complexity. They are looking for a problem solver.

How might we hire and train for problem solvers?

How might we build on and improve the role of social prescribers, care coordinators, citizen’s advice professionals, among others to support people to work through issues from health to housing?

“I think attaching a sling to the hoist is something that they're very fastidious about and they seem to double check, make sure I’m in it correctly before they go, and I'm sure all of them check, but some of them don't seem to check as thoroughly. Little things that some of the carers might not notice is that there is a load of dry laundry hanging up somewhere and I always think, a good carer would say, ‘oh they’re dry, I'll tidy them up and put them in the cupboard, and somebody who doesn't see it... it's not that they're a bad carer. They can transfer me and they’re competent, but they just wouldn't go that... It's not even an extra mile, it's an extra inch.”

INTERVIEW #4
DOMICILIARY CARE USER

QUALITY | THE EXTRA INCH

- So after, there was a nurse that came the other day, she's a new nurse. It's not like she's going to come back here, but she said, 'just in case I come back, how do we do your legs again?'. 'Oh, calm down', because I couldn't breathe properly. She said 'Don't worry. Don't worry. Take your time.' And then she's looking for the spray – she's like, 'do you have [ ]', just for extra protection. She's taking her time, she's looking at the wound, she's pressing it, and then she's dusting off my bed, and I thought, Wow! It's not like she's a new nurse and she's going to see me all the time. She was just here on site just to cover, but her nursing was very good. And I told everybody about it as well. #9

- It's not that they're doing something wrong, it's just they're not doing something, or not seeing it. #4

And on the flip side - we've heard a theme of *Carers taking the path of least resistance, and even cutting corners. (appendix)*

- He might take him out for half an hour because if I'm on holiday, and I'm here, and the carer comes in, showers him, brings him down, and then I'll say, 'go on, take him out for half an hour' or whatever, take him out for a walk, come back and then you can go, and he does twenty minutes. #12

- And then I come home from work one day, it was early. And they was supposed to be here 9 till 12, and this is about quarter to 11. And he's standing at the bus stop. And I come in, I thought to myself, why is he at the bus stop, he's supposed to be there 'till 12?

So I come in, [#12] said, yeah, he's just gone. Well, he shouldn't, he should be here for another hour and 15 minutes. Then he's seen me coming in and he's come back, 'I'm sorry, I'm sorry'. I said, 'well, why are you [ ]? You doing this every day? Are you leaving him every day?' 'No, no, no, no, no.' I said, 'but why are you doing it now?'. 'I come back. I don't want you to report me'. 'Well,' I said,

06 | DISCUSSION

THE I STATEMENTS

I feel safe from harm in my community

I play an active part in my community

I am able to breathe cleaner air in the place where I live

I am able to support myself and my family financially

I am supported to make healthy choices

I am satisfied with my home and where I live

My children get the best possible start in life

I am confident that those providing my care are competent, happy and kind

I am able to access safe and high-quality services (when I need them)

I want to see money is being spent in the best way to deliver local services

I feel like services work together to provide me with good care

I understand the ways to live a healthy life

I have a good level of happiness and wellbeing

Regardless of who I am, I am able to access care services for my physical and mental health

I have a positive experience of the services I use, overall

I am supported to live the life I want

I believe the trust confidence and relationships are in place to work together with services to decide the right next steps for us as a whole community

THE I STATEMENTS | REFLECTION

Which of the I statements are most and least present for the lives of our users described in the document?

Regarding this user group - which three I statements are the most impactful? Meaning, if 80% of the outcome for these users was dependant upon 3 I statements going well, which three would you choose?

personalised

Whether it's the NHS Long Term Plan or the Ageing Well Strategy for Tower Hamlets Council, words like 'personal', 'person centred' and 'self-supporting' appear front and centre.

power

Helping others help themselves has become a rallying cry for health and social services in Tower Hamlets. Ultimately, we are describing the diffusion of autonomy.

quality

Social prescribing, care at the right place and right time and flexibility are all ways to meet people's needs and improve health, wellbeing and quality of life.

connected

Again, intimacy and moving closer - this is not only speaking about the relationship between the social worker and the user, but also the user's relationship to their wider community.

storytelling

"Good information" in 'good ways" - accessible communication and simple ways to understand, engage with and access a set of complex system.

affection

Isolation, reduced mobility and the onset of chronic illness precede grief, depression and limitations - we want to meet those feelings and thoughts head on with courage and compassion.

THINGS TO CONSIDER (NATHAN)

Confidence to act

Capability / capacity

Information

Motivation / purpose / aims / meaning

Circumstances / opportunities / barriers

What are you thinking about when designing a care package? Are there principles to come back to when designing it?

Cost
Hierarchy | get things signed off - negotiation going on
Quality
Safeguarding
Quality of life
Autonomy
Dignity
Relationships | goals, meaning and connection - the carer
Meaning | goals | aspirations
Describing the system - storytelling

The world

connected | linked in
agency | autonomy | power

My carer

quality
peace

My care

storytelling
personalised

touchpoints

- walk-up to care
- hospital / deterioration / chaos / crisis (long run up - so what as a commissioner, is it your remit to do anything? Want to avoid chaos/black swan. Should people be planning their care in advance? What might an ongoing relationship look like, pre-care?)
- initial assessment of care package | often with social worker
- meeting and goodbye with (sometimes suddenly) a range of health and social workers (from chiropadist to nurse to physio)
- 6-week review
- literature \ letters \ pamphlets (care package details, etc.)
- Financial assessment (different department?)
- liaising with social workers
-

WHAT COMPLEXITY LOOKS LIKE (NOTES)

So with this letter from the local authority you'll speak to them at [the community mental health team]?

Yeah I'll speak to [my nurse] and ask her what's happening.

Is that who you feel most comfortable to speak to about things – [your CMHT nurse]?

Yeah, cause she sorts things out for me. Because I can't understand what they're trying to say to me. #3

why

So you were in the hospital in May – how did you end up in the hospital?

I can't recognise that, I ain't got no... I just got sick and they took me to the hospital. I was in the hospital for 3 weeks.

How were you feeling before you went to the hospital?

I was all right.

Why did you decide then to go – what was the thing that caused you to go to the hospital?

Well as I said, I took sick. I don't know. I lose my memory and things like that. I had to go to the hospital.

OK, so you don't remember why. And who took you?

The ambulance.

And who called the ambulance?

Well I think it was the people next-door who called the ambulance. Or my sister. She lives in East Ham... #10

- *When you came out of the hospital, what did they tell you about leaving the hospital... what information did they give you?*

I don't think they give me no information... they didn't give me information. They only discharged me, and then the carers take over... carers and nurse take over...

Did they explain or describe to you what happened to you... what was going on with your body?

No, no they didn't... the nurses and saying everyday [ ]... they didn't tell me. #10

my own body

Mile End Hospital. I think it's the second floor – for the diabetic people. They do the eye screening, I think they do the feet treatment. Not that I been for the feet treatment.

number of services

Okay yeah. You go there how often?

I can't remember now. It's been a while, because we had that lock down. Cause I was going quite often.

What prompts those visits or what was prompting those visits before lock down?

Because I had that pancreatitis thing, they had to keep an eye on my sugar levels, and the diabetes and that – my weight and everything.

chaos - sudden, drastic change

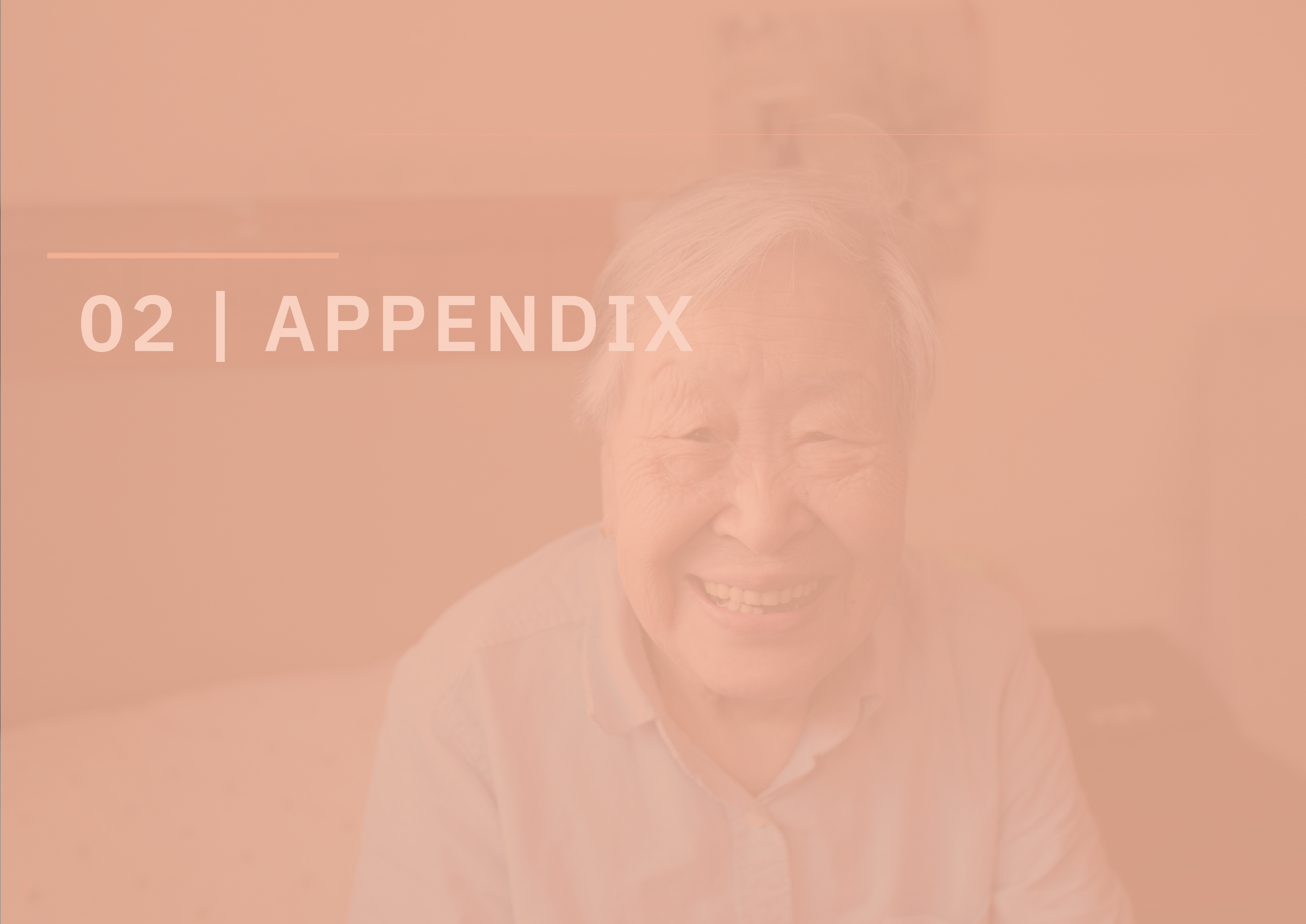
How did that change during the lockdown? How did the support... Because that sounds quite urgent. Like you need a regular check-up? How were they able to do that during the lockdown? #3

They haven't done anything, I've just been left on me own, really. Like to sort out myself.

What kind of communication did you get during the lockdown so that you could support yourself?

None. The only people I heard from are the endocrine people. I've got an underactive thyroid. #3

02 | APPENDIX



COMMISSIONING PRIORITIES CONT'D

2019-24

The NHS Long Term Plan
https://www.england.nhs.uk/long-term-plan/

1 | Personalised Care will benefit up to 2.5 million people giving them the same **choice and control over their mental and physical health** that they have come to expect in every other aspect of their life

2 | Over 1,000 trained social prescribing link workers will be in place by 2020/21 rising further by 2023/24, with the aim that over 900,000 people are able to be referred to social prescribing schemes by then. Social prescribing link workers connect people to wider community support which that can help improve their health and well-being and to engage and deal with some of their underlying causes of ill health.

3 | 200K people will have a personal **health budget so they can control their own care**, improve their health experiences and experience better value for money services over a “one size fits all” approach

4 | 750,000 people have a **personalised care and support plan** to manage their long term health conditions

5 | Develop the skills and behaviours of 75,000 clinicians and professionals through practical support to use personalised care approaches in their day-to-day practice

6 | That we deliver universal implementation of the Comprehensive Model of Personalised Care across England, which fully embeds the six standard components– shared decision making; personalised care and support planning; enabling choice; social prescribing and community based support; supported self management; and personal health budgets and integrated personal budgets – across the NHS and the wider health and care system.

2017-20

Ageing Well In Tower Hamlets: a strategy for improving the experience of growing older in our borough - Key themes

https://www.towerhamlets.gov.uk/Documents/Adult-care-services/Supporting-adults/Ageing_Well_Strategy.pdf

1 | Care and support that is truly personalised to individual circumstances, strengths and needs, and that optimises their independence.

2 | Keeping me informed in accessible ways | having good information about rights, about services and about local activities that older people can benefit from is critical to maintaining wellbeing and independence and to tackling loneliness and isolation.

3 | Ensuring that the right housing and accommodation options are available to people as they age

4 | Optimising independence and wellbeing: employment, welfare benefit take-up and reducing poverty

5 | Supporting people, as they age, to continue making a positive contribution in our communities

6 | Staying healthy and active

7 | Living well with dementia

8 | Reducing isolation and loneliness

9 | Getting the help and support I need as close to home as possible

10 | Last years of life | supporting people to die well, and in the place of their choosing

2018-19

Tower Hamlets Integrated Commissioning Aims

https://www.towerhamlets.gov.uk/Documents/Adult-care-services/Director_providerforum.pdf

"Empower people to meet their own needs"
"Enable people to meet their own aspirations"
"Improve health, wellbeing and quality of life"
"Co-produce services and care"
"Simplify the system, make it easier to understand and access"
"Ensure the right support, in the right place, at the right time – as close to home as possible"
"Be flexible and responsive to meet personal outcomes"
"Deliver value for money, making best use of resources across the system"
"Develop self-supporting communities"

2019-20

THT Ageing Well Strategy Priorities

https://www.towerhamletstogether.com/the-challenge/promoting-independence

"Embed a personalised model of care to include holistic person centered planning and the offer of a personal health budget."
"All adults living with complex needs accessing multiple health and care professionals have a coordinated approach to their care.
"All adults living with frailty in Tower Hamlets receive a joined up approach to their care from all the professionals and services who work with them."
"To improve identification and management of those with respiratory issues by reviewing current services and understanding resident experience of living with respiratory. This is a joint priority across Waltham Forest and Newham CCGs."

SUPPORTING LITERATURE

In 2016, the CQC published their report, *Building Bridges* - it says:

> *Health and social care leaders should develop and agree a shared understanding and definition of what integrated care means for the population in their local area, and then work towards delivering this shared aim.*

The report goes on...

> *...there was a considerable lack of clarity as to what care plans are; what they should include; when they should be produced and reviewed; and what their purpose is. Care plans were commonly described as being primarily about what actions health and social care professionals were taking, such as number of visits or descriptions of procedures. It was not the case that plans were always focused on setting out how services and support was being provided to ensure people's goals and preferences were being delivered. They also did not routinely include details of how older people had been involved in developing or reviewing their care plan.*

https://www.cqc.org.uk/sites/default/files/20160712b_buildingbridges_report.pdf

GOOD & BAD HELP

Nesta's Good and Bad Help outlines effective mindsets, tactics and approaches for services and social programmes to build purpose and confidence to 'transform lives.'

Good help

- equips people to take positive action to improve their lives, whether this is to find work, improve their health or to get the most out of education
- increases people's confidence, sense of purpose and hope
- involves listening carefully to what matters to people, what's going on in their lives, their skills and motivations
- it strengthens their sense of what is possible.
- enables people to take actionable steps that lead to long-term improvements in their lives

Bad help

- tries to fix things for people in the short term or encourages them to take action that fits with the service's priorities and not their own
- leaves people without clarity about the changes they want to make or the knowledge, confidence or support to get there
- often only addresses a single (and often most visible) aspect of people's lives, without taking account of what else is going on

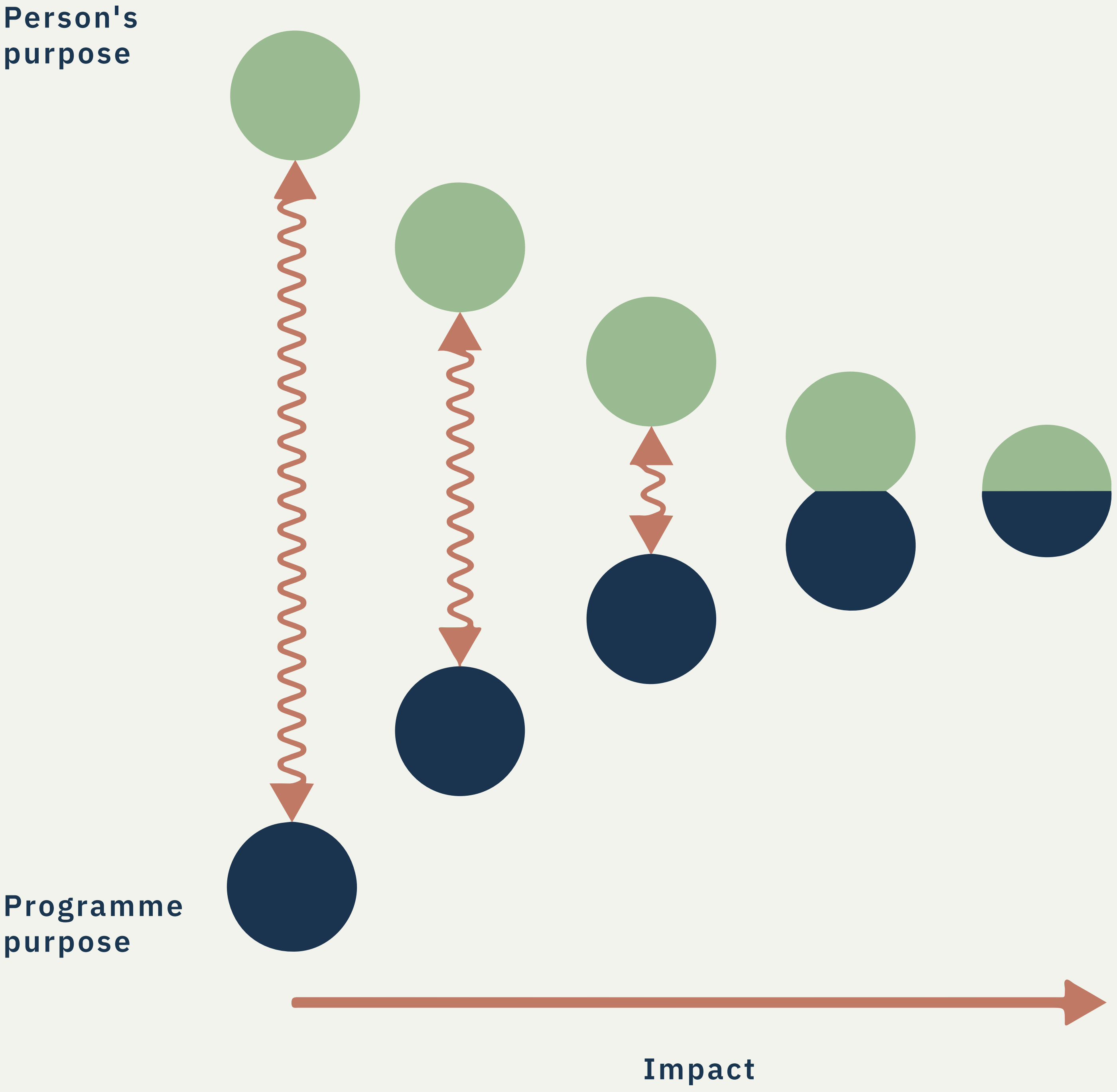


Figure 4 from the document, titled 'Alignment of Purpose' illustrates how impactful, quality support is heavily dependant on 'the help's' ability to identify and craft care around what is meaningful to the user.

https://media.nesta.org.uk/documents/good_and_bad_help_0.pdf

MAKING MEANING

An excerpt from Nathan.com...

What types of meaningful experiences do people value? In the course of helping companies develop products and services that suit their markets, every year we interview over 100,000 individuals from countries and cultures around the world. In these interviews, we've found commonalities among the meanings people feel strongly about, whether we're studying the adoption of new software in Poland or the purchase of toothbrushes in Florida.

We've compiled a list of these meanings, but it is far from exhaustive. We've found potentially dozens of types of meaningful experiences and at least as many possible ways to characterize them. What we concentrate on here are 15 of the meanings that emerge most frequently in these interviews and appear to be universal among people's values. While the relative importance of these meaningful experiences might vary and their interpretation could differ slightly, all cultures seem to recognize their significance.

1 | Accomplishment
Achieving goals and making something of oneself; a sense of satisfaction that can result from productivity, focus, talent, or status.

2 | Beauty
The appreciation of qualities that give pleasure to the senses or spirit.

3 | Community
A sense of unity with others around us and a general connection with other human beings.

4 | Creation
The sense of having produced something new and original, and in so doing, to have made a lasting contribution.

5 | Duty
The willing application of oneself to a responsibility.

6 | Enlightenment
Clear understanding through logic or inspiration.

7 | Freedom
The sense of living without unwanted constraints.

8 | Harmony
The balanced and pleasing relationship of parts to a whole, whether in nature, society, or an individual.

9 | Justice
The assurance of equitable and unbiased treatment. This is the sense of fairness and equality.

10 | Oneness
A sense of unity with everything around us.

11 | Redemption
Atonement or deliverance from past failure or decline – deliverance from a less desirable state.

12 | Security
The freedom from worry about loss

13 | Truth
A commitment to honesty and integrity.

14 | Validation
The recognition of oneself as a valued individual worthy of respect.

15 | Wonder
Awe in the presence of a creation beyond one's understanding.

http://nathan.com/making-meaning/

A HIERARCHY OF NEEDS: HEALTH

And then I come home from work one day, it was early. And [the carer] was supposed to be here 9 till 12, and this is about quarter to 11. And he's standing at the bus stop. And I come in, I thought to myself, why is he at the bus stop, he's supposed to be there 'till 12?

So I come in, [He] said, yeah, he's just gone. Well, he shouldn't, he should be here for another hour and 15 minutes… 'Well,' I said, 'I'm going to report you, because that hour and a half, he could have had an accident and there's nobody here'. #12

• *You said that at first that uh you couldn't take it [anxiety from having new people in your home] - it was a lot. How were you able to work through that or cope or how did you…?*

You have to keep on telling yourself that things are going to be OK, not to panic. You've spoken to them on the phone, so you have to keep on telling yourself that things are going to be OK.

So you've got a practice then of reminding yourself that your safe?

Yeah, and you have to teach yourself to breathe, cause when you get panic attacks, that's the worst thing you want is panic attacks. Because sometimes it seems like you're having a heart attack and you're not. #3

I can't see my back. I can't see the sore, I can just smell it and I can just tell, and then, so they listen to my instructions. Whereas I would rather they tell me, and then I will feel a lot better.

Your sense is that they don't fully understand the challenge around the wound?

No, no. Maybe a one or two of them. So, someone might come for a week and not notice, and all of a sudden someone's going to come, and say, 'oh my God, call the ambulance, call the doctor. And then I've been like this for over a week. I've been like this for two weeks. So nursing, yeah, I would say, very bad. #9

The Botox stopped, and then they give him drops to go under his tongue, but the drops under his tongue, if they didn't go under the tongue, they hallucinate him, big time. The district nurses done it, but they put it on the tongue, so I come home from work and he was really, really bad, hallucinating, had to come off of them straight away, because that was down to the nurses. #12

So after, there was a nurse that came the other day, she's a new nurse. It's not like she's going to come back here, but she said, 'just in case I come back, how do we do your legs again?'. 'Oh, calm down', because I couldn't breathe properly. She said 'Don't worry. Don't worry. Take your time.' And then she's looking for the spray – she's like, 'do you have [ ]', just for extra protection. She's taking her time, she's looking at the wound, she's pressing it, and then she's dusting off my bed, and I thought, Wow! It's not like she's a new nurse and she's going to see me all the time. She was just here on site just to cover, but her nursing was very good. And I told everybody about it as well. #9

Me and [my primary carer], we cook together now. She showed me how to cook a curry and things, so it's quite nice. Cause I watch her cook what she does, and that, and we enjoy cooking together… I can see her cooking, I can see what she's doing, so I know she's not poison me or anything like that.

What is it about cooking together that that you find meaningful?

Cause I'm learning as well, you know, because before I didn't know how to cook a curry. I just used to get curry jars, but now I learned how to cook one, I can cook and it last me a few days. It's something fresh, and that, it's not something you stick in a microwave. So it's nice and fresh, it's got fresh chicken, potatoes, mushrooms and chickpeas. And it's really nice. Instead of having microwave meals, it's really nice.

So cooking and food is an important thing for you?

Yeah, I have to be careful because of my diabetes. I have to be careful, like the sugar content, the salt content and all that carbohydrate, so you have to be careful, and I have to be careful about my weight as well. #3

And when I've looked on the side, up the stairs, he's got this spray that you use for cleaning baths and sink, not floors, and he sprayed it all over the floor. So obviously it makes the floor slippery. [He] fell over – he said, no wonder I slipped on it as well. Oh, I'm sorry. I'm sorry. I said, 'but that's dangerous'. I could have ended up with a broken leg. [He] could have ended up with a broken leg. So it's little things like that - niggly things. #12

I can't swallow… I can't eat nothing, I just, everything medicine I put everything by pipe. This is my food and other one is…

Okay, and the nurse helps you with that, is that right?

Nurse gives the medicine for the pipe.

Okay, and that's for the medicine as well?

Yeah.

Are you able to do that on your own?

No. Medicine with the nurse and for… because I can't get that. #5

Before the lockdown, she used to get people from the hospital coming – physiotherapist - just to come and sit her up and put her feet up and try and see if she can sit on the edge of the bed, and stand up, obviously with support… They wasn't told, and I wasn't told either that she wasn't supposed to put pressure on that right foot, cause it still had the sore in it, it was still in the healing process. So obviously putting pressure on it, it will just make it worse again, so they stopped coming after that because she couldn't do it…

You said that they didn't really tell you that she needed to keep the sore untouched. So how did you get all that information?

That was the nurse, the nurse was saying we shouldn't really put pressure on it… I said to the physiotherapist… and I think, obviously, I think when they went back, they started communicating with one another… the nurse said to the physio, she's not meant to put pressure on it. So the chiropodist come one day and gave her the boot to keep the pressure off of that heel. #6

I had 2 in the morning and one in the evening, and the carers failed to notice an eight centimetre by five-centimetre pressure ulcer on my bum. So when that burst I was rushed into hospital and that was October of the year before last. As a result I've had to give up work… I had worked with my M.S. for twenty-three years… luckily the district nurse came to do something else on my legs or something, and said, oh my god – phoned an ambulance straight away…. I was so poorly, I was pretty much out of action until January. #4

A HIERARCHY OF NEEDS: HYGIENE

I mean somebody who can do their job. One hour, two hours, I don't care. I mean he's doing one, two, three, four hours a week, and my house looks like that. And it's only this little room.

How do you get a sense of how the house is. How can you sense if it's clean or not?... you said for example that the carer doesn't do a very good job because he's kind of...

I can feel it. You know if you go like something like that (swiping his finger on his bed side table). And you go like that, you can tell whether it's been clean or not. Oh come on, I may be blind, but at least, I know when something is clean or not. #8

Because if you don't have that help, you're going to be like smelly, you won't be able to do things yourself. It's a lot of help... probably won't be able to do things like wash my hair, clean me legs and things like that she does for me. You know, it's about the simple little things like having a wash that they can do for you to help you... simple things like they wash up that I can't do. I can't stand up for a long period of time, wash up and things like that. I can't hoover anymore, because it all hurts your back. #3

And other things that are really petty, but I don't like people washing up because I think that... and particularly my carers, are awful at washing up, it's disgusting. I can't bear it. It's not a critical thing, because I just say, 'don't wash up' and so it doesn't annoy me, because they don't do a bad job, because I don't let them do that job. #4

Like face [towels], I got about 30 face [towels]. You use a face [towel] once, you wash it. Use a towel you washed #12 in the shower – dried, that's dirty. In my eyes that towels dirty... no, he hangs the towel over the edge of the bed. He can use that tomorrow, I went, 'no, it's dirty. He's used it once, that is it...

Yeah, like I only use a bath towel once. I don't know how many times other people use it. Face [towels], I only use it once. #12

OK, so what I'm hearing then is that you've told him that you want things done a certain way around hygiene and cleaning...

Yeah, obviously that's my... it's the way I grew up. #12

I've even asked the nurse, 'can you not send them?' And I've even told that person, I don't mean to be bad, I'm sure you're good at other things, just not my needs. I try to be nice about it - I do want to go behind their back and say, 'well I don't want that nurse'. I explain why I don't want them and what the issue is. They might be very good at giving injections, and maybe cooking, and God knows what else, but just not dressing my sores, and my needs... As long as they're trying, you can't blame them. #9

...the nurse who comes around, knows that, the weekend, she'll tell me, this bastard hasn't been cleaning up. I mean those are the words that she uses, which I agree with her. #8

[my nurse] doesn't like doing anything. I'm giving you your water... 'oh you've got water', 'no, that's old water – can I have a fresh water?' 'Oh, so you want fresh water'... you ask them, 'can I have some water', and this one 'you want fresh water', that sarcasm...

But you didn't like the fact that she didn't understand that you just wanted some fresh water?

Well, that's it.

It's a small thing, but...

It's a big thing to me, because the glass of water has been hanging around all night, which I don't need that. All she has to do, is just go into the fridge, pick up one of the bottles... 'So you want me to do that'. Well what are you here for? #8

[The carers] do not pass the hoover that much in my house, they only pass it one of the three days that they come over during the week, but one day is not enough for me because of my child

...my son is disabled, so they (carers) only pass the hoover once a week, but since my son is disabled and he cannot even walk on his own. He uses something like crutches to help him stand, but I help him.

So, does your son usually sit on the floor?

Yes

Why is it important that there is regular house cleaning?

I do not need it every day, I would need it at least two to three times a week, because the house gets dirty, so passing the hoover once a week is not enough and my son plays around on the floor. #2

A HIERARCHY OF NEEDS: RHYTHM

I'm so used to getting up at half 6 in the morning, going get into work by 8:00, 8:15 and starting a day, and I think I need that... sort of a little bit of structure. Otherwise I'm sort of, you know... like today, for example, the district nurse was late, so now it's two o'clock and I haven't done anything, other than at a quarter to seven this morning, I had a shower, washed my hair. And that was it. You know and I sort of think, ughh. And then by the time it gets to four I think, tomorrow. And every day is tomorrow sort of thing. #4

No, because you can't shower on the day that [carer's are] not coming, which I don't like bed baths and it just doesn't feel the same to me. I'm used to getting up in the morning and having a shower. #4

Sometimes problem because sometimes they come in 10 o'clock, 11 o'clock, too much late. Because I eat three times the food, 12 o'clock and 4 o'clock. Afternoon I give the one medicine. Last time they come at 10 o'clock and 11 o'clock... Three nurses is okay but two nurse, they are new people...

So you need 3 or 4 hours after the medicine to eat?

Yeah.

Is that right? So if they come too late, you can't eat on time?

That's the problem, nurse sometimes coming late... #5

If the church were to open back tomorrow, I can't go, because I got to wait her for the nurses and the carers, you understand what I mean. All them things, you know, I would like to get up to church and things like that...

The carers come back here at 12 o'clock, by that time, I'd be in church. But I thank God for what they have done for me. #11

Oh, yeah, they're good. I'm not a machine, or I'm not a cat. You can't just leave food and go away. Like when I'm hungry at different times... Do you see what I mean? #9

Well I used to drink, smoke, all kind of things that was bad... womanise. Since I accept Christ, I live a Christian life. Before I was sick I used to go the church up the road here, and we had to leave there, so Wembley. So before it was closed... all the churches closed now, but before I was sick, I used to go to Wembley on Sundays...

When you go to church, what does that do for you?

... church and pray... help you to live a decent and Christian life. That's what the church does. It's really good to me. It helps me a lot... even with my sickness. [ ] prayed for me, and all that and help me to where I am now.

How so, can you give me an example?

It helps me a great deal, because when you're a Christian, you don't do things that you normally would do, like gambling and things like that, you just live a Christian life and live Christ alone. #11

Christian radio she listens to. Christian Radio – Premiere Radio she listens to... There's a guy who comes on after the news, at nine o'clock. After nine o'clock news he preaches basically the word of God and that's weekly - that's every day. And on a Sunday now, 8:00 in the morning there's a lady who comes on...

#6: Pam Rhodes, Pam Rhodes. She conducts the service [Songs of Praise – BBC].

Pam Rhodes – 8 o'clock on a Sunday morning.

What do you like about Pam?

#6: She's all right (smilling). I'm used to her because when I used to go to church, I used to listen to the service...

Mum, why is it important to go to church?

#6: Because I believe. I believe in the Bible.

How do you feel when you listen to the shows on the radio now?

#6: All right, sometimes I know the hymns that they play and I sing to them... I know some of them that they have on the radio... Happy. I'm accustomed to it. #6

A HIERARCHY OF NEEDS: RELATIONSHIP

What's your relationship like with these 10 or 11 people? How would you generally describe your relationship with them?

There is no real relationship. Just come and do their job, and then go, as quickly as possible.

You sense that people come in, they do their jobs quite quickly and then they leave?

Yeah, they don't stop and chat.

Years ago, I used to have a carer... come from a different [care agency]. And she used to come and she didn't need to do anything, just sit there for an hour or so and talk with me.

Why do you remember that particular carer, why was that meaningful?

Cause she come and talk to me – no other carers do. I thought it was quite nice, because she spent the time, even though she didn't have any physical thing to do.... #1

Good thing I can laugh because at the moment I'm so depressed...

Are you able to communicate that to your carer?

Yeah, and I'm on antidepressants, but I'm so immune to them. They don't do much for me. If I didn't have my partner, my friend and my carer, I might as well say goodbye. #10

The carer. Yeah. I said if I didn't have her help, I don't think I'd be alive today, because she looks after me...

As soon as she comes in, I mean she mops every day, she washes up, she won't let me do my own breakfast, she spoils me... she does everything. When she sees I'm a bit sad, she gives me a hug. She's loves me. I'm like a mother to her. And she's such a lovely woman...

Yeah, [my carer's] absolutely a diamond, if I didn't have her coming here, I wouldn't have no life. I wouldn't be able to cope.

How often does she come?

She comes every day, seven days a week. Twice [a day]. She'll be here tonight. Bless her, she's dedicated to me. She's fantastic. Best friend in the world to me. I love her so much as a friend... She's such a wonderful person. As soon as she comes in she cheers me up. She was singing this morning as well. #10

What do you think of your relationship with your carers?

My relationship is good, and they are good to me. I have a friendship with them, and I like to chat with them too.

What do you like to talk to them about?

There are so many things we talk about – cooking, life stories and domestic life. #2

I fall down and I twist on my back, and I broke [my ankle]. So actually, all this section of the leg... put together. And then she arranged some people, it's not like she was a social worker, she was a human being.

I didn't have this phone you know that – land line, but I had the mobile anyway. I begged them, she rang them up, and I had the telephone land line. And she would ring me up every day... 'how you doing?' 'Oh, I'm doing all right'...

You were concerned for [your social worker]?

Of course, you know if somebody concerned about you, you're concerned about them as well. Vice versa - one hand washes another.

It sounds like you'd built a close relationship with her...

Yeah, because... I don't know how to explain to you. In my land or in my life, anybody who does something for me, I would never leave them on the roadside. #8

He's a lovely guy. Don't get me wrong. He loves him to bits. He looks after him, no problem at all. #12

He loves this [nurse], she's lovely... I know this one's lovely, and he loves this one, but she's not here all the time. She's only here like once a week or twice a week. #12

A HIERARCHY OF NEEDS: MEANING

And is that the first time you had carers?

I never have them in my life.

[family member]: He has always refused them, he has always wanted to do it himself normally.

I never have before carers.

Have they offered you carers previously?

[family member]: Yes, he has always declined. He has always wanted to be independent. And we had us helping, we're constantly helping, the whole family, we've got a big family. #13

What are some specific things that happen on a good day?

I feel better when my carers take me outside... I feel better when I go out. I get to speak to other people too.

When you go outside, what do you like about being outside?

I like to be in nature. #2

Any other specific things you want to share?

I need another house, because this flat is very old. My daughter she joined me already in this flat. She live with here, not regularly, because the [indiscernible] no good, plus problem in this room [indiscernible] very small, so I need two, three bedroom house – I want if it is arrangement for housing people to talk to you, then in future my daughter and my son, school teacher, and my daughter, they are buying.

So you would want more space, and more space would allow for your son and daughter to live with you – why is that important that your daughter and son live here?

They'll look after me. They'll look after me. #7

Yeah, one's a rescue cat - the black one that was here. I've had them both since they were little – they're both like my little babies... I love my cats. They're the reason I get up in the morning – I feed them, I talk to them. People think I'm mad when I talk to them. #3

I'm OK, I got my TV, I got my music, my guitar, my organ. What the heck do I need?

You play guitar?

Yeah.

How long have you played?

Years and years and years and years. Well the first band I play with was [JW] Band. We play at the Empire Ballroom in London. And then [he] retired... [Alan Taylor] I play with him, and we played in Hammersmith. Hammersmith Ballroom, cause all these empires, they were all in the same company... #8

Is there anything that you feel like you need just generally in life right now that would help you?

Well all I want in life is to get back to my normal health. Get back to the man I used to be.

What would that look like? How do you know that you would be your old self? The man you used to be.

Well it would be a great achievement for me... [indiscernible]... have to do things for you. It would mean a great deal to me.

You would have more of your independence – you wouldn't need help.

That's right, that's right.

What do you feel like you need to get to that place? What will help you get to that place?

Well I think the grace of god will help me to get there. It's hard when you're a big man, and you've got to depend on people to do things for you. That's more like kids do, innit? Well it's just one of them things.

Yeah. To know I used to do these things myself... [ ] do them things for me. But with the grace of god, I will get there. #11

And what would you do usually if you didn't have the catheter?

I like to walk. #13

I've been playing, because we go to the church in Mile End... Obviously, with the lockdown, it's been closed, so they've got an online service, so I've been going on that on a Sunday, playing it to Mum, and she's been listening to it, because she recognizes the voice of the pastor, and so she listens to his readings, his prayers, the singing sessions. So she listens to that on my phone. #6

How are you feeling about being able to go outside more regularly?

Better... fresh weather is important part of life. #7

That's the problem now, I can't bring my wife because she does not understand English. She can't take ESOL test.

So she would need to pass a test to come?

But she doesn't understand so she can't coming.

What do you want for you wife and your son?

I want to bring them here, because I can't go by plane because I got another stroke maybe I dead. So I can't go... it's so hard... I don't know how to bring them here. #5

I'm marking it out now, and I'm going to cut a square out and put another square in...

So it sounds like you used to do quite a bit with tools...

[family member]: Mm, he used to be a carpenter, he used to be a builder. So, he thinks he can still do that sort of stuff. We keep telling him...

So it sounds like there are some things around the house that used to be important. You're still trying to take care of things.

Still think I can still do it, but I...

[family member]: He can't do it basically.

How do you feel, because you know obviously that your body is...

Very degrading. Keep telling me, you can't do it, you aint doing it. #12

HYPOTHESES

The last 24 pages are a collection of hypotheses developed from a number of curated quotes from the 13 interviews.

Hypotheses in the design process are testable through further listening and learning - they are either validated, further developed, or nullified.

These are the cornerstone of the learning cycle, as they help create a picture of reality from which we can effectively design a high-fidelity solution.

HYPOTHESES

I feel really cared for, and I feel an affection for my carers/ nurses

- #12: Then [R] come the other day, the other nurse...

He loves this [R], she's lovely.

- What now? Yeah, now. As I say, we got no issues with the guy... the carer's lovely. #12

- The nurse is very nice. No trouble, no nothing. Come here every single day, the nurse, and try to help you. #13

My situation is such that I don't believe I have the capability, encouragement nor opportunity to progress/move forward/find motivation to find meaning.

- Currently, I can't walk – I can't support my own weight. It's the reason I'm in bed. But apart from that, that's all...

97

1997?

Yeah. 1997 is when I got the MS, and 2015, when I couldn't walk anymore... stuck in bed all the time since 2015.

Since 2015 you've been bed bound?

Yeah.

And how has your care changed over that time? The care that you're receiving and support?

The same, I think. Yeah.

So you haven't found much change over that time?

No. Afterall, I don't go anywhere, so there's no change. #1

- I haven't really have any goals, because I just think I got this for the rest of me life... it's only going to get worse, so what can I do.

Who do you speak to about that or about your plan for your care?

Sometimes with [the nurse] and sometimes with my psychiatrist, and sometimes I just keep hold of things. Cause I think no one can help me. #3

- *How's that been done for you, then, being inside so much for the last five or six months?*

I don't give a damn. The world can go around... I've been around people. Well now people can go around me. Screw them.

So you're okay with being inside...

I'm OK, I got my T.V., I got my music, my guitar, my organ. What the heck do I need?

You play guitar?

Yeah.

How long have you played?

Years and years and years and years. Well the first band I play with was [ ] Band. He was so bad. We play at the Empire Ballroom in London. And then [he] retired...

[ ] I play with him, [ ] Band, and we played in Hammersmith. Hammersmith Ballroom, cause all these empires, there were all in the same company... #8

- #12: I'm marking it out now, and I'm going to cut a square out and put another square in...

So it sounds like you used to do quite a bit with tools...

Mm, he used to be a carpenter, he used to be a builder. So, he thinks he can still do that sort of stuff. We keep telling him...

So it sounds like there are some things around the house that used to be important. You're still trying to take care of things.

#12: Still think I can still do it, but I...

He can't do it basically.

How do you feel, because you know obviously that your body is...

#12: Very degrading. Keep telling me, you can't do it, you aint doing it.

We've let him try, you know what I mean. There was a little thing. He said, 'can I paint?', I say yeah. I give him the paint, the paint brush. It was like a hook. They didn't have the colour we wanted. So I got it, I said, right, you can paint it. He missed half of it, but it was paint everywhere. And I said, well, you can't do it. #12

Time and attention to creating a relationship is important. That also shows me I'm truly being cared for. Relationship is defined as meaningful connection, not simply presence. Being a human being, not just a worker.

- *What's your relationship like with these 10 or 11 people? How* would you generally describe your relationship with them?

There is no real relationship. Just come and do their job, and then go, as quickly as possible.

You sense that people come in, they do their jobs quite quickly and then they leave?

Yeah, they don't stop and chat.

Years ago, I used to have a carer... come from a different [care agency]. And she used to come and she didn't need to do anything, just sit there for an hour or so and talk with me.

Why do you remember that particular carer, why was that meaningful?

Cause she come and talk to me – no other carers do. I thought it was quite nice, because she spent the time, even though she didn't have any physical thing to do.... #1

- *Can you tell me when you feel like you're really being taken care of? When do you have a sense that the people around you - the support - is really taking care of you?*

I don't know. They're just there. That's it, they do their job, and they go.

Your sense, again, is that people come in, do what they're supposed to, and then they leave.

Yeah. #1

- *What do you think of your relationship with your carers?*

HYPOTHESES

My relationship is good, and they are good to me. I have a friendship with them, and I like to chat with them too.

What do you like to talk to them about?

There are so many things we talk about – cooking, life stories and domestic life. #2

- I fall down and I twist on my back, and I broke [my ankle]. So actually, all this section of the leg... put together. And then she arranged some people, it's not like she was a social worker, she was a human being.

I didn't have this phone you know that – land line, but I had the mobile anyway. I begged them, she rang them up, and I had the telephone land line. And she would ring me up every day... 'how you doing?' 'Oh, I'm doing all right'. #8

- *You were concerned for [your social worker]?*

Of course, you know if somebody concerned about you, you're concerned about them as well. Vice versa - one hand washes another.

It sounds like you'd built a close relationship with her...

Yeah, because... I don't know how to explain to you. In my land or in my life, anybody who does something for me, I would never leave them on the roadside. #8

- The carer. Yeah. I said if I didn't have her help, I don't think I'd be alive today, because she looks after me...

As soon as she comes in, I mean she mops every day, she washes up, she won't let me do my own breakfast, she spoils me... she does everything. When she sees I'm a bit sad, she gives me a hug. She's loves me. I'm like a mother to her. And she's such a lovely woman. #10

- Yeah, [my carer's] absolutely a diamond, if I didn't have her coming here, I wouldn't have no life. I wouldn't be able to cope.

How often does she come?

She comes every day, seven days a week. Twice [a day]. She'll be here tonight. Bless her, she's dedicated to me. She's fantastic.

Best friend in the world to me. I love her so much as a friend... She's such a wonderful person. As soon as she comes in she cheers me up. She was singing this morning as well. #10

I can't read and or comprehend what has been sent to me. I'm either partially blind, I don't speak/read English, and/or I'm dyslexic.

- *And what's your relationship like with your GP?*

It used to be all right. But now you can't phone them up and talk to them, you have to go through e-consultation and you have to fill in all these things before you can get to speak to your doctor or before you can get your medicine. Whereas before you used to be able to phone up your GP and ask them to call you back and speak to him. That's all changed now.

What's your feeling about that?

It's a bit long winded just to speak to a GP. And if you're dyslexic, you know, you get confused and that...

Yeah, she phoned me in the end, but I had to do this e-consultation twice to get somewhere. #3

- I don't know - they sent me a form, but I'm dyslexic and I can't understand it. They give you option things, but I don't understand it. #3

- Because that's the other fear, with looking for a new employer is that I can't see, you need to load two bits of fancy software just for me to be able to turn it on. It's all right when you're with an existing employer and that happens, because they look out for you, but to go to a new employer... not only do you have a wheelchair user, but a blind one. It's not ideal. #4

- *...what kind of impact does dizziness have?*

Actually, when it started, I can't see properly

You can't see properly?

Yeah... sometimes, too much dizzy, I can't see properly. #5

- *How quickly did your eyesight deteriorate then from being able to see some things to not being able to see at all?*

Well actually I can see you here [looking up close at his hand]. I can see my four fingers. Right here I can see only that and that... The table I can see the white. #8

I have routines of doing things like hoovering a certain number of times a week, and I can no longer control that - I've lost autonomy, so I have to engage in a discussion with gate keepers.

- There are three carers that come to see me, and then one to see my son. When I ask if they can pass the hoover for three days, they don't acknowledge it. [My primary carer] and another lady normally do all the cleaning. #2

- Because if you don't have that help, you're going to be like smelly, you won't be able to do things yourself. It's a lot of help... probably won't be able to do things like wash my hair, clean me legs and things like that she does for me. You know, it's about the simple little things like having a wash that they can do for you to help you... simple things like they wash up that I can't do. I can't stand up for a long period of time, wash up and things like that. I can't hoover anymore, because it all hurts your back. People don't realise when you got a back injury, it hurts. #3

- I'm so used to getting up at half 6 in the morning, going get into work by 8:00, 8:15 and starting a day, and I think I need that... sort of a little bit of structure. Otherwise I'm sort of, you know... like today, for example, the district nurse was late, so now it's two o'clock and I haven't done anything, other than at a quarter to seven this morning, I had a shower, washed my hair. And that was it. You know and I sort of think, ugh. And then by the time it gets to four I think, tomorrow. And every day is tomorrow sort of thing. #4

- ... because of my M.S. and other things you have to rush to go to the toilet and rush your shower in the morning and rush... whereas normally you'd have a coffee, maybe sit on the loo,¬ have a shower a bit later, you know, it's the flexibility, which and that's not the case. That's just the M.S., and the fact that it... because the M.S. determines I need care, you know, it's not the carer's fault that I can't sit on the loo for an hour, reading a paper and then having a shower, or not go to the loo, but then later on sit on the toilet and get in the shower again - I can't do things like that. And other things that are really petty, but I don't like people washing up because I think that... and particularly my carers, are awful at washing up, it's disgusting. I can't bear it. It's not a critical thing,

HYPOTHESES

because I just say, 'don't wash up' and so it doesn't annoy me, because they don't do a bad job, because I don't let them do that job. #4

I am at times completely reliant upon my care (carers, nurses, the agency, etc.) to communicate my needs, and especially for vital things like my health and bills – and I don't even communicate them or know how to.

• *Who helps you communicate that need to [your carer's] and other people outside of the house?*

I do not have anyone.

Do you not take anyone else's help?

No, I do not have anyone.

For example, if you need to make a doctor appointment, who can help you do that?

No one helps me, so I rely on the receptionists to speak Bengali.

Do you do it on your own or does your carer help you?

My carers help me.

Do you have specific examples of when you needed a translator to help you?

Doctor appointments and sometimes with my bills. #2

• *So with this letter from the local authority you'll speak to them at [the community mental health team]?*

Yeah I'll speak to [my nurse] and ask her what's happening.

Is that who you feel most comfortable to speak to about things – [your CMHT nurse]?

Yeah, cause she sorts things out for me. Because I can't understand what they're trying to say to me. #3

• *How much do you speak to [your primary carer] and the carers regarding the plan for your health and if you speak to them at all about that?*

No, I tend to keep things to me self. I just let them know how I'm feeling that day... I tell them if I'm in pain, or if I'm OK. That's as far as it goes. #3

• *Are there things that you guys are kind of working towards for your health and mobility?*

Not really, they haven't really mentioned it now. Because she's been the way she is for such a good while now, I'm not even sure she'd be able to even... even though she'd have support on each arm to hold her, I'm not sure if she'd even be able to balance now, because she's been bedridden for so long now, so I'm not sure.

Because obviously, being the way she has been for so long, obviously, her strength might not be as strong as it used to be... and the balance as well. They haven't said anything, so I don't know. #6

• So like my food, sometimes he is not giving delivery so I call, but my speak, these people sometimes not understand me.

So some people, it's hard to understand...

Carer is okay.

How does you carer try to understand you better?

Because he is Bengali.

Okay, do you find it easier to speak in Bengali?

Yeah. Because sometimes my voice people not understand. So like, my voice don't come properly. #5

• *Okay so it doesn't come properly. Are there times when he says "I don't understand you", does he say that to you?*

Sometimes people say. Not understand proper.

Okay, how has that worked for you? How are you able to communicate?

Actually, there's people coming regular, these people know what I need. That's it. So nurse coming and looking at the book, she check the book and medicine and everything. So carer coming and sometimes when I tell her that the bath whatever I need it. So I tell her one time and she does the same thing every time. #5

• I mean there was a young lady who used to work [at the agency], before, and she used to contact me constantly. Say, 'how you doing, blah blah blah.' And she'll be on their backside. Kick their backside to make sure. Now I haven't got the faintest idea. I've been kicked from pillar to post. It's like they collect money and I just live [indiscernible].

So when there was this woman who was holding carers more accountable, you noticed that the care was better at that point?

Oh I haven't got the faintest idea... you know when you give up on somebody, it's like if you're gonna speak to one person who doesn't relay the message to even if they're not dealing with you, but you don't relay the message to the next person who is supposed to be dealing with you. I find that is useless. #8

• *How late does he usually come?*

I can guarantee you, it will be up to 2 hours.

2 hours late usually – he's late? What time is he supposed to come usually?

Well, actually, we never said that bit, but we talked... I told him, I'd rather have an early morning, which consists till about 11:00. I would say that.

So you'd prefer that he comes before 11:00?

Yeah, about 11 ish.

And that gives you the chance to have the afternoon to yourself. So what time will he usually come?

I mean, I even had him turn up about 6 o'clock... evening. Who turns up at 6 o'clock in the evening? #8

• It's the nurse who are putting the injection. If you have supposed to complain anything, you have to take the nurse and the nurse to come to...

Communicate to the doctor?

... to the doctor.

HYPOTHESES

You find if you are able to say to the nurse and the nurse then speaks to the Doctor, then you can...

Yeah. Anyway, I don't think the nurse going to do anything. Somebody tell me 'why don't you tell the nurse?' One of the friends, and I listen to them. The nurse come here. He been twice here, this nurse. I said so, so, so, pain my legs. Look my legs. Look, look, my leg's like that, because I stay all night. The nurse, he report to the doctor, and the doctor come here... #13

I don't believe I have options/power/autonomy to get my needs met (e.g., if I say what I need, I'll lose my care).

- *So do you have any choice in that? Have you expressed that concern to [your care provider]? I mean what does he say when you ask that?*

Do I have any choice? Of course everybody has choice. It was either cancel the whole shebang, or just shut the fuck up and put up with it.

So you feel like you have to just put up with it?

That's way I felt, at that time. #8

- Tower Hamlets needs to look at these pullups for disabled people. Why are they only allowing two a day? Like, that's disgusting. In my eyes it's disgusting, two a day. And they know some people have four a day, six a day. You know what I mean? And I think that's where [#12's] getting all these water infections from in his urine, because where he's sitting in the pads, and he's obviously frightened to change them, because we've got to go out and buy them. Like twelve weeks eight packets, and he can use a packet in a week.

What did your doctor say...

They've all tried, even the district nurse, she come around to me last Friday, she said, 'I've been in touch with the Mile End Hospital who issues them, and they turned around and said, no.' All they're allowed is two of them, but the other ones he can have as many as he wants. Well, they're no good, so we might as well stay with what he's got. #12

I am very capable of communicating what I need – and I do.

- I'm very vocal, so if there's someone... I noticed actually, earlier on, my carers gone on holiday, so they wanted to send cover, and she came before, but I just didn't like her attitude, because sometimes she's in a good mood and sometimes she's in a funny mood for no apparent reason, so I just told them, I don't want her. #9

- *It sounds like you are quite proactive in working with the carers themselves to move the schedules around, and make sure you get what you need. And how do the carers respond to that?*

Oh, yeah, they're good. I'm not a machine, or I'm not a cat. You can't just leave food and go away. Like when I'm hungry at different times... Do you see what I mean? #9

- I've even asked the nurse, 'can you not send them?' And I've even told that person, I don't mean to be bad, I'm sure you're good at other things, just not my needs. I try to be nice about it - I do want to go behind their back and say, 'well I don't want that nurse'. I explain why I don't want them and what the issue is. They might be very good at giving injections, and maybe cooking, and God knows what else, but just not dressing my sores, and my needs... As long as they're trying, you can't blame them. #9

- I said, do me a favour, there's your iPad, 'go, I don't want you here no more.' The carers gone, 'why is she screaming like that?' I said, 'she's a horrible nurse.' #12

I can and do coordinate my care directly with my carers (not even the agency).

- *You said that you're quite vocal, and you said that you're willing to express when you're not satisfied. Who do you communicate that to?*

With the carers really. I don't have much contact with the agency, cause I've got no issues, no complaints and if I do I just tell the carer. But if I do have complaints, there is... so I've got 2 numbers for the care agency where I can speak to them directly. #9

- My carer, her brother is not well, so she has to go to see him all of a sudden, so rather than someone else come in, and by the time they get used to me and my ways and their ways, the two weeks will be over, so I ask, and the carer knows me quite well, so we're managing between the night carer and another carer, so she will do the day shift, and then somebody else will do the night shift, so we're all just sorting that out at the moment. #9

I am alone/lonely in London (or in my home).

- I don't have any relatives; I only have my son...

Do you feel alone at home?

Yes. #2

- *Why would that be important [that your children live with you] – that they take care of you? Why would that be a good way to live?*

Because I am lonely living like a [indiscernible]

It's difficult to be alone?

Yeah. #7

- Then I'm joining them, I'm feeling relaxed, so I understand my daughter is here, my son is here.

So you would feel like you can relax?

More, yeah. Now I suppose carer gone, you gone, after one by one cigarette.

Do you find you smoke more when you're by yourself?

Yeah, alone, because thinking coming.

Thinking – you find that when you're by yourself, you're thinking a lot?

No, not that. Thinking suppose everything – thinking, where is my son? Where is my daughter? How their position now? Plus, this house's problem – leaking, broken, plus they told me to apply to the council, and tell them wheelchair, you'll need a big flat, big door... #7

- *So you've got a few friends around...*

Yeah, but I still feel a bit lonely. Do you know why I'm getting this loneliness? I'm a peculiar person. Good thing I can laugh because at the moment I'm so depressed... #10

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Living with someone can be similar to living alone.

- No, my son is disabled...

How old is your son?

24

Does he play around on the floor?

Yes, he does not understand, so he plays around on the floor. #2

- *How does your mum feel about...*

She is already sick. She got diabetes and (high blood) pressure and so many problem...

And when she has to help you, how does she feel about it?

Hard for her because she is about 84, so hard for her sometimes. #5

- *I understand. So your wife now is in the hospital?*

Yeah, my wife is in the hospital now.

[family member]: Yeah, she had a minor stroke

How long ago was that?

[family member]: Monday [a week prior]. Sunday, actually, she had this problem, Sunday. She wasn't feeling well. Well that's what grandad said. Then Monday he called us to come, she didn't recognise none of us – she was just staring at us. We called the ambulance and they come here. They tested her and found that she had a mini stroke – very mild. Now they took her in and she's there now. #13

- Because my wife, she's a very sick woman. She can't cook. She can't walk. #13

Getting outside is vital – either to breathe and be in nature and/or to connect with others – and going outside can be dictated by cost of care/care plan.

- *What does a good day look like? What are some specific things that happen on a good day?*

I am okay, and I feel better when my carers take me outside.

Do you feel better when you go out?

Yes, I do

Where do you go?

I just go around my area, and [my carer] takes me outside.

I feel better when I go out. I get to speak to other people too.

What do you like about being outside?

I like to be in nature. #2

- I like going out for walks... Monday, Wednesday and Friday, I do like to try and get out and walk if I can. You know, sometimes it's not possible, but it's the only bit of exercise I get – a bit of fresh air that I get. Otherwise no one really comes to visit. It's been hard since the lockdown. #3

- *Are you able to go out by yourself?*

No, I don't go out by myself. #3

- *How are you feeling about being able to go outside more regularly?*

Better... fresh weather is important part of life. #7

- *So you feel things will be much better when you get your wheelchair?*

Yeah. Less pain, and with pain, if somebody takes me outside, I need to do. Last 9 months I'm not going anywhere, in this room.

So you haven't moved much in the last 9 months?

No, no move.

Has the pain been more for the last 9 months?

More. More pain. #7

- *And what would you do usually if you didn't have the catheter?*

I like to walk. #13

I need exercise.

- What I need. The first thing I need is actually somebody to go down to this place... Argos – get me their catalogue. God damn, then at least, I can order something like exercise machine, or something, that can [ ] me indoors...

What would that do for you if you had something like that?

Well at least my circulation would be better. #8

There is a cohort who know for some time that they very likely will need care and support – there is a long transition time to dependence on care for some.

- *So how long how long have you been in the current situation?*

97

1997?

Yeah. 1997 is when I got the M.S., and 2015, when I couldn't walk anymore... stuck in bed all the time since 2015. #1

- I've got multiple sclerosis and I've been in the wheelchair for many years and I've had care probably for the last 12 years and used to have care in the morning so that I didn't tire myself out before going to work and for safety... I was rushed into hospital and that was October of the year before last. As a result I've had to give up work... I had worked with my M.S. for twenty-three years. #4

- I was diagnosed about 26 years ago or something like that. And I was okay for the first sort of six or seven years, and then it started affecting my mobility, and I then bought a little one bedroom flat, ground floor, and that was okay. I was starting to use Zimmer Frames and walking sticks. And then I moved in here having bought it knowing pretty much I was going to end up in the wheelchair. #4

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- I've got slight cataracts, but I don't need to have an operation on them yet. #10

How important is the relationship with the GP? (I don't even want to recall the name of my surgery) – it can go one way or another (GP may also be responsible for the thing I want the most).

- *What's your relationship with your GP?*

Haha, what relationship. No, GPs these days are [ ] as they come.

I don't have a GP, it's the GP practice. One of the people turns up occasionally. Not very often.

They come with the district nurses?

Not usually.

What does the GP usually visit for?

I don't remember. The GP I haven't seen... or even been there. I've never been to the surgery. It's somewhere over there.

Do you know the name?

The word 'green' comes to mind... #1

- *So he's been pretty proactive in making sure you get what you need?*

Yeah, and in fact I've lived outside of his catchment area for about 20 years, but I've stayed with him, because at the time that I was moving from where I lived in E3, Bow, to E1, I was moving and I would have crossed the boundary of the health authority. It was is in the days when they had, not trusts, but I can't remember what it was called... and it meant that I would have moved from one health authority to another, and he was concerned that because the GPs fund the medication that I was on at the time, which was quite an expensive M.S. drug that was at the time considered to be maybe postcode lottery type. You know when you hear of some people can get a particular drug in that borough, but not in that borough sort of thing. The drug I was on was one of those ones that was sometimes a bit contentious, so just to avoid... I didn't know whether the new health authority would say yes or no. Or the new GP would say yes or no. But just to anticipate it not working out he said, 'just stay with me'...

Yeah and they have actually made home visits here, which normally wouldn't happen because I'm outside of the GP catchment by quite a way. But he has... he came over when I was ill with this. #4

- *Can you give me an example of when the GP has come?*

Last 4 months ago, came once a time, and a few days ago, I spoke with her. I speak with her, they arrange the wheelchair for me for go outside for fresh weather.

The GP arranged that?

Yeah. After exam. After leg exam. Arthritis in my leg. #7

- *You get that from the GP?*

GP and mental health medication from the mental health doctor.

Is there anything that you would want more of or less of?

The ibuprofen gel, if anybody suppose...

How do you get the gel?

The doctor, GP. And they deliver it to me. #7

- Yeah from the GP, for 9 months I call every single day, every cream I have here. Nothing that works. They never help me to find out how to get that one. They give me something else.

Did they not understand it was bed bugs?

[family member]: Maybe they don't. I don't know what they understood but they weren't doing nothing about it. #13

Carers doing what they're supposed to do – that is the minimum, and it is also not necessarily a high-quality level of care. And that is also, potentially, what is expected from the users and families.

- *What is the social worker there for? What is your feeling about her? What is her role?*

Well her role, basically, is just to see... what's the word, basically to kind of care, like make sure mum gets the care she needs and support, basically.

Have you had to reach out to her at all since Mom left?

No, no...

Do you feel like you've needed to at all or that you've wanted to?

No, not really. Not really, because as I said, the carers come and do what they're supposed to do, and so there's no need really. #6

- It's all right. They haven't done anything wrong with me, so they're all right... they haven't done anything to get upset with them. #6

- *And how is that process for you, transition to this kind of new setup and new support?*

Um, it was OK, it was fine, it was OK. I never had any issues or problems with it – it's fine. They just come in and do what they have to do, and I do what I've got to do, so, yeah, it's fine. #6

- Yeah, I think there is - just disorganized. You know I was left off the list today. They come every other day, the district nurses now, which is in my opinion not great, but they come every other day. #4

- ...the nurse who comes around, knows that, the weekend, she'll tell me, this bastard hasn't been cleaning up. I mean those are the words that she uses, which I agree with her. #8

High-quality care requires attention and the extra inch – and I don't care what is health and what is social, I just want quality care.

- I think attaching a sling to the hoist is something that they're very fastidious about and they seem to double check, make sure I'm in it correctly before they go, and I'm sure all of them check, but some of them don't seem to check as thoroughly. Little things that some of the carers might not notice is that there is a load of dry laundry hanging up somewhere and I always think, a good carer would say, 'oh they're dry, I'll tidy them up and put them in the cupboard, and somebody who doesn't see it... it's not that they're a bad carer. They can transfer me and they're competent, but they just wouldn't go that... It's not even an extra mile, it's an extra inch. #4

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• It's not that they're doing something wrong, it's just they're not doing something, or not seeing it. #4

• He's good person, if I need anything, he try to help.

If you need anything he tries to help?

Yeah.

What, can you give me an example of when you needed something and he was able to help?

So like when the post, when I send a letter to somebody... can you send that one when you go home and do the post it, or if he anything about the surgery, if I can't go, so I send the carer and he send the message to doctor that he needs the medicine or whatever. #5

• There's only two rooms, kitchen, here. And he said, 'here's done', knowing that I'm blind and I cannot see, so how can... it's like some kind of abuse. I don't want to get rid of him yet.

Your carer?

Yeah, till I can get somebody real.

If he was gonna do a better job or you said someone 'real' what do you...

I mean somebody who can do their job. One hour, two hours, I don't care. I mean he's doing one, two, three, four hours a week, and my house looks like that. And it's only this little room.

How do you get a sense of how the house is. How can you sense if it's clean or not?... you said for example that the carer doesn't do a very good job because he's kind of...

I can feel it. You know if you go like something like that (swiping his finger on his bed side table). And you go like that, you can tell whether it's been clean or not. Oh come on, I may be blind, but at least, I know when something is clean or not. #8

• [my nurse] doesn't like doing anything. I'm giving you your water... 'oh you've got water', 'no, that's old water – can I have a fresh water?' 'Oh, so you want fresh water'... you ask them, 'can I have some water', and this one 'you want fresh water', that sarcasm...

But you didn't like the fact that she didn't understand that you just wanted some fresh water?

Well, that's it.

It's a small thing, but...

It's a big thing to me, because the glass of water has been hanging around all night, which I don't need that. All she has to do, is just go into the fridge, pick up one of the bottles... 'So you want me to do that'. Well what are you here for? #8

• And then there's another carer that I had that used to work with me quite a while back. I've asked her to come on and so hopefully, they said she can apply, and then they'll just keep an eye out for her application, and hopefully try and... cause she knows my ways as well. She worked with me quite a while back. She's quite good, and we've stayed in contact. #9

• So after, there was a nurse that came the other day, she's a new nurse. It's not like she's going to come back here, but she said, 'just in case I come back, how do we do your legs again?'. 'Oh, calm down', because I couldn't breathe properly. She said 'Don't worry. Don't worry. Take your time.' And then she's looking for the spray – she's like, 'do you have [ ]', just for extra protection. She's taking her time, she's looking at the wound, she's pressing it, and then she's dusting off my bed, and I thought, Wow! It's not like she's a new nurse and she's going to see me all the time. She was just here on site just to cover, but her nursing was very good. And I told everybody about it as well. #9

• [The carer] is a lovely guy. Don't get me wrong. [#12] loves him to bits. He looks after him, no problem at all. But there has been a few issues, like with the tools. Why was he doing that? You're here. You know you're not allowed to. #12

• And when I've looked on the side, up the stairs, he's got this spray that you use for cleaning baths and sink, not floors, and he sprayed it all over the floor. So obviously it makes the floor slippery. [#12's] fell over – he said, no wonder I slipped on it as well. Oh, I'm sorry. I'm sorry. I said, 'but that's dangerous'. I could have ended up with a broken leg. [#12] could have ended up with a broken leg. So it's little things like that - niggly things. #12

Carers are taking the path of least resistance, and even cutting corners.

• It got to the stage, the carer wasn't taking him out, [#12] might say, 'no, I don't want to go out', and the carer was taking notice. Even when the weather was really nice. He was saying, 'no I don't want to go out'.

And then I come in and he says, 'I've been sitting here all morning'. I said, well you're not sitting in front of the television from like three or four hours at a time, because he puts them in the chair, and I said, 'no, you need to go out'. You need to go out and get a bit of fresh air.

#12: We literally walk around Wapping now, cause we can go to the tower, turn back at the tower and come back down [ ] and Wapping Lane, so there's nothing really going on...

He can walk him anywhere in three hours... you don't have to just walk him across the road and then bring him back...

He can go to the tower. You know what I mean? He can walk him right across the tower, he can walk him right up, there's a little market, Watney Street. He can walk him to Watney Street Market within three hours, because they've got all the... he's in a wheelchair. They've got all the ramps, so the carer can do that, but he isn't. He's taking him to watch the boats. I would get fed up with it, you know what I mean? Watching the same thing, going to the same place every day. #12

• He might take him out for half an hour because if I'm on holiday, and I'm here, and the carer comes in, showers him, brings him down, and then I'll say, 'go on, take him out for half an hour' or whatever, take him out for a walk, come back and then you can go, and he does twenty minutes. #12

• And then I come home from work one day, it was early. And they was supposed to be here 9 till 12, and this is about quarter to 11. And he's standing at the bus stop. And I come in, I thought to myself, why is he at the bus stop, he's supposed to be there 'till 12?

So I come in, [#12] said, yeah, he's just gone. Well, he shouldn't, he should be here for another hour and 15 minutes. Then he's seen me coming in and he's come back, 'I'm sorry, I'm sorry'. I said, 'well, why are you [ ]? You doing this every day? Are you leaving him every day?' 'No, no, no, no, no.' I said, 'but why are you

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doing it now?'. 'I come back. I don't want you to report me'. 'Well,' I said, 'I'm going to report you, because that hour and a half, he could have had an accident and there's nobody here'. #12

- Yes good, they're mostly good people you know. You find the bad and good you know. Have the carer here who stole my money.

[She] stole your money?

Yeah, I have £50 one in my jacket for eat, buy something, food, you know? Had £120 in my pocket. One day he stole the £50, two days I never looked my jacket, I never been out. My jacket I have the £120 and he stole it. I report him to the people. #13

- She come here, and my wife is [ ] because she have the accident, the hip accident, and she can't walk properly. And this girl, anytime she come here, she's supposed to be working, '... please let me go home because of my children' this and that... I said watch this carer, because she is something [ ] to you, and that happen.

So if I understand correctly, she was asking to go home early?

Yeah, every single day, 1 minute, 2 minutes, 5 minutes, like that.

[family member]: Yeah, and was only here for a few minutes, she was supposed to do 45 minutes, she was doing about 5 minutes and then she off, go. And that's why they find out. I've witnessed it myself. #13

- *Why was he good?*

Well he used to be able to do his job properly... he would clean up. But nowadays it become slackish. Because he knows that I cannot see. Because before this situation, my eyes, I would be able to see certain things. And I would tell him, that's not right, that's not right, that's not right. #8

- Yeah, every Wednesday, one hour. Every Wednesday. I don't care about these people - 1 hour he working, but most people is not working properly. No, no. He send the people here to do this and that, but they not doing that. Supposed to be the carers to come here and clean the place.

[family member]: We end up doing it.

To do the bed. But he's not doing these things.

Okay, so you don't think that he's doing what he's supposed to be doing?

[family member]: He's not doing his job. #13

Good care is understanding and getting used to the importance of details, and the complication and risk associated with certain tasks.

- And the routine is very complex – the routine and technique as well, and because it's quite complex. I can't just have a carer take over. If it's just like getting my food ready, or helping me sit up and stuff, it's different. But this is like putting the pillows under my legs, and doing this, and doing that, and getting pressure off my backside. So yeah, it's very complex. #9

- ... First of all it's a breath of fresh air that they all speak English, because before that I was with an agency – only one person spoke English, so you had to [ ], but the council threw them out. #9

How Coronavirus/ the lockdown has impacted people.

- I've got six grandchildren.

Is that them over there?

Yeah.

Lovely. How often do you see them?

I used to see them once every couple months, I stay over there. They live in Harlow. Because of this lockdown, I haven't seen them in very long while. I miss them, but at least they photo call me and I can see them all when she photo calls me... I call it photo calls, when I can see them.

Why haven't they come during the lockdown?

Because my son doesn't want them to get that Corona thing... just being protective.

Yeah, he's a bit concerned. How are you feeling about the last few months and four months?

Not really too good, like I said, if it weren't for my cats I wouldn't be here. #3

- The doctor helps me with that and I go to the hospital for that – Mile End Hospital. I think it's the second floor – for the diabetic people. They do the eye screening, I think they do the feet treatment. Not that I been for the feet treatment.

Okay yeah. You go there how often?

I can't remember now. It's been a while, because we had that lock down. Cause I was going quite often.

What prompts those visits or what was prompting those visits before lock down?

Because I had that pancreatitis thing, they had to keep an eye on my sugar levels, and the diabetes and that – my weight and everything.

How did that change during the lockdown? How did the support... Because that sounds quite urgent. Like you need a regular check-up? How were they able to do that during the lockdown?

They haven't done anything, I've just been left on me own, really. Like to sort out myself.

What kind of communication did you get during the lockdown so that you could support yourself?

None. The only people I heard from are the endocrine people. I've got an underactive thyroid. #3

- I did have a centre I would go to, Bow Haven, but that's been closed down since the lockdown, it's been closed down. Bow Haven. That might be shutting down due to funding. So that means I will have nowhere to go. #3

- *So there was minimal contact with you from all of these people during the lockdown? How did you feel during that time?*

Been feeling pretty low really. I told the nurse that I was feeling pretty low. I've had contact with someone called [M], but I can't remember where she's from or who she is, but she phones me up a lot.

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What does she help you with generally?

She talks to me and she's getting someone to phone me up and talk to me.

How did you get in touch with [M] originally?

She got in touch with me, so I don't know. #3

- I've been playing, because we go to the church in Mile End... Obviously, with the lockdown, it's been closed, so they've got an online service, so I've been going on that on a Sunday, playing it to Mum, and she's been listening to it, because she recognizes the voice of the pastor, and so she listens to his readings, his prayers, the singing sessions. So she listens to that on my phone. #6

- I probably need to look for some part time work or something, because I've just wasted... lockdown – I've made lockdown a reason for the last four months, but the 12 months prior to that is hmm ahh, I have been quite lazy. I haven't been particularly well, but...

... Yeah, I just feel that since I stopped I sort of gave myself a couple of months, and then it was six months, and then it was nine months, and it's like oh hang on, I really need to be a bit more productive get online and look at maybe getting work or something. #4

- *So you didn't go outside not one time?*

No, when it started, the coronavirus, I am not going out. Because problem is, I am scared about the Coronavirus.

You're scared?

Yeah.

What did you hear about the coronavirus?

Because I could not before look after... because carer coming four time, nurse coming two time, but I am not going out about the Coronavirus because I got the problem, no one look after me. My mum is old. #5

- When is before virus, I call the doctor for emergency so doctor coming. Now, doctor not coming. They give the address [to someone]. So last week I [went to] the hospital. The doctor take my blood one month before and doctor call me [to say that] my blood short... I don't have much blood in my body.

Because he know I got problem with... So I tell him because my hand and my feet, I can't extend like that...

So you knew something was not right and you told the doctor?

I told the doctor, he take the blood test then after he send me hospital for these people. #5

- Some people scared about the... Some people they won't go outside, because sometimes you can't check it. But I check it, everything is fine.

Everything is okay. And how has the last 4 months been because you've had to shield yeah you've had to be inside?

Yeah, I am in the room, not going out.

And what has your experience been like during this time with your carers and with all the support?

Because the problem is, before my carer take me the out 1 hour. Now when virus coming, he is not take the risk. Because if anything happen... Doctor told me to not go out, better for... #5

- I just stay in the room, no difference about that, nothing. Because 7 days the week I stay in the room. #5

- Actually, since sometime before that, since I found out there's some, what you call it, some flu going around. I just said, alright, let me stay out – I don't want no... but until that, the only people I have is two or three friends, and the rest of them are dead anyway, I think. The ones I hate are dead. The ones I loved, they are dead as well, but there's only a few of them left anyway. #8

- When I had an appointment with Moorfield's [but because of the pandemic] all my appointments been cancelled, and now I have to wait till November or December.

So you lost eyesight or your full eyesight around January and then obviously the [virus] hit, so you haven't really had a chance to go to Moorfields [and be checked out] properly. What are the nurses doing or the doctor - you haven't spoken to the doctor about that?

My doctors closed up 24/7... might as well break into the Bank of England. #8

- *Who are you able to speak to about your depression? Is there anyone you can speak to?*

Well not really at the moment, because I joined a club that I've been going to for 33 years, but that has been closed because of this Coronavirus, and the manager she comes there every week, but I haven't seen her for a fortnight. I might try and phone the club tomorrow...

What's the club?

...it's a club, mostly elderly people, a lot of them have Alzheimer's and dementia, but it's a wonderful club, because I was funded three days there, so I didn't have to pay. We have activities, entertainment 3 times a week, and a kitchen, you have a meal, you got your friends there, different activities. It was like a second home to me that club... #10

- I used to go to a diabetes check every, I think, every year or every two years, but I haven't been now since this Coronavirus. You can't go in the hospital... so they phone me at the time and discuss everything with me.

They called you. Where is the diabetes clinic?

Well my diabetes clinic is in Mile End... Mile End Hospital. But they told me to go to my surgery last month. Chrisp Street Health Centre, but then they phone me back and tell me, 'don't leave home, stay at home and they will phone me'. So they phone me and ask me how I was getting on, things like that. #11

- *That's been a year with the catheter?*

Over a year.

[family member]: because of the virus, they don't bother to take him in.

They sent me 4 appointments after this and everyone cancel.

Okay, why were they cancelled?

I have no idea.

[family member]: Because of the virus. #13

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- Yeah because I used to put in my own injection, everything. After I had this virus...

[family member]: He's saying that since the virus, he's stopped putting it himself

I used to do my injection my own.

Until the virus?

The virus come and start the nurse to come here, the rest is carry on.

[family member]: Basically she's carried on from there, he hasn't done it since. #13

- *How did you guys find lockdown with him and how was that?*

[family member]: We was coming nearly every day and bringing him food... 3 times a week. #13

I'm experiening limited mobility and physical ability – pain, arthritis, muscle atrophy, etc.

- I tried to go out yesterday and we had to keep on stopping, I got a wheelchair down stairs in the shed... we had to keep on stopping, because it felt like it was just gonna come out (pointing to her hip). It's like really hurting, and it's getting stuck. It's getting stuck and you get like a stabbing pain, so we had to keep on stopping. And then I had to come back home because I felt sick. She said, is it the diabetes sickness, and I said, no, it's not the diabetes, it's just like, I feel sick with the pain. #3

- Yeah or sometimes my mobility scooter, less so since I've had the pressure sore - I've not been able to use mobility scooter, which has been a pain. #4

- It isn't as easy now that I can't use... I used to hop on the scooter and be able to do everything and now I can't, because of the pressure sore. It stopped me using that. I can't transfer, and particularly because I'm shielding and the current distancing. I've actually not really been out of E1. But I get around by wheeling, which is one of the reasons I don't have an electric wheelchair is that I like... it's a bit of exercise, I suppose, because I don't do much. So most the time I wizz around on this. If I go out, I go out in this... I haven't done anything like that for ages now, but if I go out to a restaurant or a pub or something... and then sometimes we'll get a black cab if I'm going a little bit further afield. #4

- And that's the one thing that I'm struggling with without the mobility scooter. I was coming to get cabs to go and see people that I would normally see from work, or after work, or meeting in the city or Spitalfields and places like. #4

- Yeah, and the leg, it doesn't go up properly.

Your leg?

Yeah, because I can't walk. Because I've got the frame, just walk the living room, toilet, that's it. #5

- I can't swallow.

You can't swallow?

No, I can't eat nothing, I just, everything medicine I put everything by pipe.

Okay, so all of your food comes from the IV?

Yeah, this is my food and other one is...

Okay, and the nurse helps you with that, is that right?

Nurse gives the medicine for the pipe.

Okay, and that's for the medicine as well?

Yeah.

Are you able to do that on your own?

No. Medicine with the nurse and for... because I can't get that. #5

- *Tell me about your situation now?*

Not very well, always pain in my leg. #7

...Who usually helps you with your leg?

Nobody. Sometimes, I need, but not regular possible, because I have no energy, no power in my body. #7

- *When do you feel relief?*

I suppose when I'm taking my pain killer, then relief something – little relief, but it's still hurting. #7

- I don't like to go to my account every day, or anything like that. I go down once every two weeks, or something like that, draw enough money, like a couple hundred quid, just put it in the [indiscernible] (he alluded to the fact that he stores his money on his bed somewhere – like his pillow). Do a little bit of shopping. That will continue my life...

How do you get down to the cash machine?

The cash machine – usually I ask somebody, like usually when certain home help comes around – not all of them – certain ones.

Of your carers?

Yeah. #8

- Yeah, it was drastic. He's saying, he can't get out of bed. And that's why I got in touch with the occupational health again and I said to get a bed that sits up like a chair. So she said, 'well, we can try one of the recliner chairs, but the recliner chair only goes back so far. I said, aint you got one that can be used in the bedroom, and use it as a bed? And at least you know he's going to sit up in a sit up position, but they don't do a bed like that.

So your mobility #12 has reduced quite drastically in the last four or five months?

Yeah, big time, big time. #12

What is meaningful are the commitments to family, loved ones | I've made a promise to those I love.

- I promise me mom I would stop smoking, because they couldn't get my breathing under control, and I said to me mom, I won't smoke no more. Cause she said, promise me you'll sort out your smoking. Said, I promise you I won't smoke. And I kept me promise that I won't smoke. #3

- It sounds like you made a promise to your mom to stop smoking. It sounds like you are focused on eating well to take care of your

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body, because of your diabetes. What is the motivation for you to keep up your health and to keep these promises to yourself?

I don't want to end up in hospital like I did. My family didn't think I was going to make it. I was in intensive care for five weeks and I didn't know anything was happening around me. People were saying things around me and that. Like my other son and his wife were arguing over me bed. I didn't even hear that going on.

…

Yeah, because they thought I was literally going to die. And they said I had blood transfusions and that, so it was quite hard for them to watch I suppose. Especially for my son's, it affected my son's really badly. #3

- That's the problem now, I can't bring my wife because she does not understand English. She can't take ESOL test.

So she doesn't understand English, so she won't be able to take the ESOL language test.

Yeah, yeah but she can't coming… because she can't because the… what is it… the ESOL.

So she would need to pass a test to come?

But she doesn't understand so she can't coming.

What do you want for you wife and your son?

I want to bring them here, because I can't go by plane because I got another stroke maybe I dead. So I can't go… it's so hard… I don't know how to bring them here. #5

- I try to go to talk to the lawyer, problem is, I can't go in the solicitor now, because you have to give the… the carer and the solicitor is too much money cost. #5

- If I go to talk to the solicitor, before he make the legal aid, now he charge the money, £1,000, £2,000.

You are not able to afford?

No, I can't afford because I sent some money about the… my son going to college, book everything. Plus he is not living in the place, he live the town, for the rent everything. So I have to pay the money to college. #5

There is one person I reach out to/go to when I need support navigating the system and/or figuring out what to do next about any particular situation (it may or may not be an intimate relationship) – some of these relationships I'm heavily reliant upon.

- I don't know - they sent me a form, but I'm dyslexic and I can't understand it. They give you option things, but I don't understand it.

If there's something like that, who do you get help from?

Well I normally phone up [my nurse], but I've left her a message, but she hasn't got back to me.

Who's that?

My [community mental health] nurse. And she hasn't got back to me. I phoned her up ages ago, and she didn't get back to me. #3

- *Who do you speak to about that or about your plan for your care?*

Sometimes with [the nurse] and sometimes with my psychiatrist…

So with that then with this letter from the local authority you'll speak to them at 3 Colts Lane.

Yeah I'll speak to [my nurse] and ask her what's happening.

Is that who you feel most comfortable to speak to about things?

Yeah, cause she sorts things out for me. Because I can't understand what they're trying to say to me. #3

- *Who do you know can support you with that issue?*

No one – I was hoping your colleague would have helped… and help me sort this out, but she never came.

Who was that?

[F]… [F] from the council.

What's [F's] role in the council? How did you originally get in touch with [her]?

I phoned her. We've had [ ] before.

Did she help you with something previously?

I don't recall. #1

- *And your social worker – did you have him or her before the pressure sore?*

Yeah, I have her constantly, although I did phone the other day, because I'm concerned about the works [adjustments to her home – lower counter tops] and she said, 'well it's all been approved'. And I got the impression, and this might be me being sensitive, but I got the impression that she was like, 'well, my job with you is done now'. I don't know. #4

- I am going to raise the issue about the flat and phone my social worker back, and just say look I know I'm not on your current agenda, but I think I need to be.

So a couple of things there - one is that you mostly communicate with the social worker when you need something?

Yeah, yeah, and mostly by email. #4

- *Can you give me an example – social worker is ok, carer is good – what does doing a good job look like?*

Suppose, when you tell the [care provider] – when he come take him to… please arrange one-hour morning, one-hour evening for escort him to do for wheelchair, when his wheelchair is coming. Then you start doing one hour in the morning, one hour in the evening.

They've changed the package – the care plan?

Yeah. #7

Building intimacy and trust with carers (and other workers) is vital and it takes consistency and time – it supports calm, and getting needs met. For some, new people can be overwhelming.

- *How about with the two carers - what's your experience like with them generally?*

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I get on well with [my primary carer]. The other one, cause she's new, cause I find it hard to trust people, I still haven't built trust with her yet, because she's new, but [my primary carer] I've had for 8 years now.

What do you not trust the other lady with?

I just find it hard to trust people.

Are there specific things around the house or generally that you are concerned about, do you have an example of something that you wouldn't trust her with?

It's just a personal thing, you know, like you know when you meet someone you can trust someone – you get a basic instinct with someone, cause I've only had her for a little while. She's nice. I'm not saying she nicks anything, like that, I just got to build up trust with her like I did with [my primary carer] – I had to build up that trust with her for ages.

... What about [my primary carer] helped you build that trust - what was trustworthy?

She got talking to me, and that, and she come in and she done her work, and that. She was alright. It's just you build up that trust with someone after a while, you know... It just happens after a while, you trust someone.

It sounds like there was something there about there was enough time and also she was consistent.

Yeah.

It's just a stranger come into your home and you're just being used to being on your own, you know, and then someone else comes in to your home. #3

• *So you have a series of people coming into the house - what's your feeling about people coming into the house and what's your relationship to that? How does that feel for you?*

At first, I couldn't handle it - it was strange. And before you were turning up, I was thinking, please let [my carer] turn up first, and then that way I got someone else here just in case anything happens, because I got to trust them first. These are all thoughts going around in my head. #3

• *So you trust a few carers then?*

Well I trust a few carers, because I've known them for long. #8

• First of all it was a bit of up and down, because mum was getting different ones, so by time she gets used to one, there'd be a different one. And now they've kind of settled it now. So she's got a few permanent ones, so she's kind of used to them now. #6

• *You said that at first that uh you couldn't take it [anxiety from having new people in your home] - it was a lot. How were you able to work through that or cope or how did you...?*

You have to keep on telling yourself that things are going to be OK, not to panic. You've spoken to them on the phone, so you have to keep on telling yourself that things are going to be OK.

So you've got a practice then of reminding yourself that your safe?

Yeah, and you have to teach yourself to breathe, cause when you get panic attacks, that's the worst thing you want is panic attacks. Because sometimes it seems like you're having a heart attack and you're not. #3

• *Okay, so you feel like you have pretty consistent needs and the carers and the nurses can identify what you need pretty seamlessly?*

Yeah. The people, long time now.

Because they've been working with you for a long time now?

Yeah. #5

• For someone to come to your house and stay with you and sleep with you, you know, you got to trust them. And also because I have very bad spasms as well, so they need to get used to me, like just how to do my legs. #9

I don't trust that I can say what I need – I'm worried I'm creating a probem and that I may lose my care.

• Because they're not doing their job, but a bad hand is better than no hand as far as I can say it. If there's no one there to give me a hand.

Do you feel reluctant then to speak out for yourself because you're worried...

Well, of course, cause if I get rid of them, who is there? No one is there. It's going to take me a hell of a long time to get somebody.

So your sense is that if you push and try to get some new carers or get rid of the current carers or the nurses that there's just not going to be someone there?

I'd rather have somebody bad.

What makes you think that that's the case, that if you ask for what you need that actually they're just not gonna show up at all?

I've seen situations like that, because one of my friends was living in Poplar years ago. There was people working for him, you know, helping him. He got rid of them and it took him years and years and years to get back that credibility for them to send somebody else. I don't know if it was [my care provider] or the council or... I didn't go into that detail. #8

• And if I create this problem I'll be taken ten steps back, which I don't want that, or I don't want to create a problem for somebody... Well just say nothing or shout out loud. If I shout out loud, it's worse for me and it's worse for them. #8

Telling your story to new people is a task – trust building must also begin again.

• From then on, you know, once you've lost one friend – you get used to one friend telling your problem, and then somebody else take's over, and it starts all over again right. I mean surely there must have been notes that [my old social worker] left behind for him.

So you've noticed that it's been a difficult transition from [your old social worker] to this new guy?

Well this new guy is more or less asking me, can we start all over again! #8

• *What is he asking you that tells you that he doesn't have any notes?*

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Really, all my complaints are supposed to be there. Hospitals, this, that, that, supposed to be there, and he's not reading it. He must be sitting on it. Haven't got the faintest idea what the heck is he doing in that seat.

He's spoken to you about things that [your previous social worker] already knew and...

We've moved it, we've dealt, we part with it. And then found a better job, which I don't regret for her. #8

For some, having people in the home is no big deal – potentially an indifference and/or resilience to the change.

• It's not really been a problem. When they, I just do what I have to do elsewhere and they just come and do what they have to do. It's not a problem, and I'm used to it now anyway. #6

• *And how many people might you see in a week or a month?*

In a month, different people, probably up to eight different district nurses... yeah eight or nine different nurses. #4

I don't trust those around me, I'm suspicious, and even my carers.

• I find there's more people who are my age and having a problem with the eye sights complaining of people talking to them and saying I'm from yada, yada, blah, blah, blah, blah... I used to have a whole huge collection of plates. You know things like people bring me? Presents [indiscernible] in the kitchen. And they keep on disappearing. #8

• [my neighbour] [H]e's shifty. #8

• *So there's a few carers that you give a lot of responsibility to?*

Nowadays I give them... I find them a little bit shifty.

How so?

Well when you buy a whole set of plates, and they say I'll do the washing, and you find out... have a look in the kitchen – have a look in there. Does it look like somebody cleaned up? No.

So you don't trust some of them... or is it all of them?

Some of them. #8

• *Do you feel like you trust the carers now?*

No, no, no, no way.

[family member]: He has to keep an eye on them. He don't trust anybody.

I sit here now properly [on this particular sofa]. If I look who going in my room and who not going, yeah.

[family member]: Because he used to sit there where you are.

Okay so now you watch.

I have the camera now. #13

People are living on a shoe string - every little bit is important.

• I got a taxi card that takes you there and brings you back. You got a number you phone on the taxi card and it comes and picks you up. You pay one pound fifty to go there and you pay one pound fifty to come back. That's a lifesaver that is. #3

• So problem is money sometimes – end of month all payments coming due that day, from the beginning to that day. Half week is ok, half week is crisis. #7

• I'm waiting to find out if I've got to pay when they've upped [my husband's care], because last time when we had nine to 12, they wanted like £120 a month. And I said, well, what do you mean £120 a month? I said for 4 days, so they was only doing like 12 hours. I said, forget about the carers. I said, how can I pay that if I'm paying £700 rent, I'm paying everything else, I only work part time. I said, and you want me to pay for a carer and other people, they are getting care and they don't pay for it. Well we want proof, so I had to send all the bank statements in, obviously when it's direct debit, the rent and all that – and we got it back and we didn't have to pay. #12

• I don't mind paying like twenty quid a month for something or whatever I can afford. But I only get like £800 a month and my rent is like 700.

Yeah, so it's tight?

Yeah, very tight. #12

Memory is a challenge.

• Yeah, a man used to come here. I forgotten his name - I forget things a lot. #3

How long ago was that?

I think that was a year ago, maybe two or three. I don't know. It was a while though. #3

• *Why did you decide then to go – what was the thing that caused you to go to the hospital?*

Well as I said, I took sick. I don't know. I lose my memory and things like that. I had to go to the hospital.

OK, so you don't remember why. #11

Vital information is at times not communicated, or communicated properly – into and out of the system.

• *You didn't have Coronavirus?*

I think it's more to do with the diabetes than the Coronavirus. I don't think I had much of the Coronavirus. #11

• Before the lockdown, she used to get people from the hospital coming – physiotherapist - just to come and sit her up and put her feet up and try and see if she can sit on the edge of the bed, and stand up, obviously with support. She done that for a little, but she felt a bit giddy, like light headed... They wasn't told, and I wasn't told either that she wasn't supposed to put pressure on that right foot, cause it still had the sore in it, it was still in the healing process. So obviously putting pressure on it, it will just make it worse again, so they stopped coming after that because she couldn't do it...

You said that they didn't really tell you that she needed to keep the sore untouched right. So how did you get all that information? Did that come when you left the hospital. Who is communicating all these things?

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No, that was the nurse, the nurse was saying we shouldn't really put pressure on it… I said to the physiotherapist… and I think, obviously, I think when they went back, they started communicating with one another… the nurse said to the physio, she's not meant to put pressure on it. So the chiropodist come one day and gave her the boot to keep the pressure off of that heel. #6

• Apparently, they get a handover… but when they come, they don't seem to know anything, and then when I hand it over, I have no dressings, so we have to use big dressings that cover my whole backside. So I say, 'can you tell them tomorrow to get some more dressings?' The next day it will be like, 'oh, nobody told me.' And it will be like, 'the sore is smelling today, can you tell them to get Silver tomorrow – it's going to get infected. I'm starting to get a temperature.' I've got to tell them, 'I've got a temperature, it's getting serious, it's getting serious.' Then all of a sudden the right person might come. And then they'll pass the message on and then they'll hand it over. #9

• I don't know who organised, but I get them from the time I got here. I think they came here and tidied up the place before I even got home.

They were here already?

Yeah, so I think the doctor must have organised that, I don't know.

Was there someone who talked to you when you left the hospital who told you you're going to have…

No, nobody told me that I'm going to have care workers.

So when did you find out?

As I said, when I got home. #11

• *But when you were going, why were you going to the hospital?*

I been twice to the hospital and they said to me not enough urine and they sent me home. And they said to me that in a couple of days, you coming back again. I come back and they keep me in the hospital 2 or 3 days, he sent me home again and he said to me arrive to you again. He arrive to me and give me the appointment and I am going over there.

And they cancel again?

And they cancel again.

So were they going to take the catheter out?

No, no, he's not take the catheter out. He leave this. The little one here, not the big one. The big one I have in the night but the day I have all the time this.

So the idea was that they would take the catheter out?

[family member]: They supposed to, yeah. But the doctor said that some people can have it for life, some people they can remove it. Basically, it wasn't clear. We didn't know really what they was doing.

They kept saying to me, arrive to you, arrive to you, arrive to you, arrive to you. Arrive to me four times but every one he cancelled. #13

• I'm going over there, there were thousands and thousands of people over there. [ ] there's not enough urine, not enough urine. I don't know what I'm going to do. I'm going crazy you know. Everyday home, everyday home…

Find the excuse… too many people, too many people… I have not enough urine. They find the excuses every time I go over there.

[family member]: Basically, what he's saying is that they were using that as an excuse to get him out and they kept saying to him 'not enough urine' and that's why we can't do nothing at the moment. That's basically what he's saying. #13

• I go crazy sometimes you know, I can't go anywhere. She's over there, I feel like a yo-yo you know? What can I do?

You feel like a yo-yo? Why is that?

I can't understand why I have this [catheter].

Okay. It's frustrating when you don't understand fully what's happening.

All the time the appointment is cancel. I can't believe this. When I go to the hospital, I complain to the doctor and they said to me that 'no, you have to stay in the hospital to check properly, stay in the hospital 2-3 days'. And I said I want to go home, I don't want to stay here, what am I going to do here? He doesn't do nothing, he said he was going to check me, but he never touch me. I can't understand to stay over there in the hospital… And they say you want to go home, then I send you home. The next day he send me home the next day.

But he wasn't able to explain to you why you were there?

No. #13

• I have nothing, no body, no pain, no nothing, why am I in the hospital? Why they keep me in the hospital to do something about it?

[family member]: He thinks he's healthy so why should he have that? The problem is they didn't explain why they this stuff into him. They didn't tell him why exactly. Are they going to stay there, are they going to remove it, he doesn't know. #13

I'm confused/ unsure about my health and my care generally. I don't know where to go or who to speak to for what I need, much of which comes down to too much information and too much complexity in the system (or not enough at times) | something more central and cohesive, like an MOT would serve me best.

• *So the nurse comes every day to give you the tablets. What are the tablets for?*

Oh it's diabetics… it's what they call like a blister pack. I've got the faintest idea what the heck… because I got diabetes. I'm supposed to have how high blood pressure, which I've not been tested lately… Look, I need MOT. If I was an old car, I'd be brought down to the scrap. #8

• *What else has changed for you during the Coronavirus?*

The doctor, I haven't been to my doctor for over a year. They've moved over on Dean Cross Street… Whitechapel, I still don't know where. They don't get in touch with me properly either. #10

• *How would you go about getting a doctor's appointment – you said you'd like to speak to the doctor?*

… **I don't know** cause they moved to Whitechapel… they sent me a paper, but I lost the paper, so I don't even know exactly where the doctor is now. I don't know how I'm going to find out, unless

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you can find out.

Who would you ask usually? You said you don't know where the doctor is?

I could ask the district nurse who comes tomorrow – they might be able to find out for me if it's possible. #10

• This could be the diabetes causing this. Who knows. That's why I won't go to a doctor, because I'm [ ]. I could badly do with a proper good medical, but [ ]. #10

• *Is there anyone you can speak to about your sleeplessness?*

I don't know – it could be my doctor... I need a proper check-up. #10

• *So you were in the hospital in May – how did you end up in the hospital?*

I can't recognise that, I ain't got no... I just got sick and they took me to the hospital. I was in the hospital for 3 weeks.

How were you feeling before you went to the hospital?

I was all right.

Why did you decide then to go – what was the thing that caused you to go to the hospital?

Well as I said, I took sick. I don't know. I lose my memory and things like that. I had to go to the hospital.

OK, so you don't remember why. And who took you?

The ambulance.

And who called the ambulance?

Well I think it was the people next-door who called the ambulance. Or my sister. She lives in East Ham... #10

• *When you came out of the hospital, what did they tell you about leaving the hospital... what information did they give you?*

I don't think they give me no information... they didn't give me information. They only discharged me, and then the carers take over... carers and nurse take over...

Did they explain or describe to you what happened to you... what was going on with your body?

No, no they didn't... the nurses and saying everyday [ ]... they didn't tell me. #10

I am receiving vital information from informal networks – friends, family, etc.

• Someone told me about if you go the solicitor, tell them you are disabled. So try to... the solicitor take care advice about free legal aid to make the passport or bring family about application to bringing family here. So how do I get legal aid?

• *So someone said to you that you can be eligible for legal aid?*

Yeah.

And who was that that told you?

A friend, he is coming sometimes. Um, he is coming sometimes. 1 month, 2 month after, sometimes coming.

This is a friend from the neighbourhood?

Yeah, he's living around Tower Hamlets.

How did you meet your friend?

He coming sometimes here. It's long time I've known him. #5

Timing of care is not necessarily supporting what is meaningful in people's lives.

• If the church were to open back tomorrow, I can't go, because I got to wait her for the nurses and the carers, you understand what I mean. All them things, you know, I would like to get up to church and things like that...

The carers come back here at 12 o'clock, by that time, I'd be in church. But I thank God for what they have done for me. #11

Nurses show up at times without notice and off schedule – at times without a need to.

• Their communication is not very good, because there was one that come during the lock down. And we didn't even know she was coming, she just come. And she said she's a District Nurse, she's come to look at Mom's foot. She come in, and before she even looked at Mom's foot, I said to her that mom's been discharged, there's nothing there. I said, 'you can have a look if you want,' so she did and there's nothing there enough. And then a little while afterwards another one come, same situation, and then another one come today. Same thing again. #6

• *You mentioned that you didn't know they were coming?*

No, they didn't say they were company. They used to when there was a problem, like when Mom had an ulcer on her foot, they used to phone. Not all the time, but most of the time they did. Say, oh, they'll be coming today or whenever they're coming. But then, as I said, as for the last three times they've come during the lockdown. No one's phoned or said anything, they just turned up. #6

The nurse's time is more flexible (autonomous) than carers (carer schedules are more regimented and prescriptive), and some care tasks are 'nurse-dependant', so they require the nurses to do something first. This makes the carer's time less valuable and more rigid and fragile. The slip in time can also have a big impact on my day. It makes me think the nurses are inconsiderate.

• *So how often does that happen where the district nurse doesn't come when they're supposed to?*

Oh, I mean I've been unfortunately under their care since October of the year before last and we did meet in February of last year to say we need to really tie down, because I'd gone back to work and so I can't... and they were coming... I wasn't able to get into work until about midday every workday, so they made it quite difficult. So they were quite disciplined in coming before 10:00, but that slipped and then it was the new year and they were short staffed and then there was Covid, and now it just seems to be the norm, and it's just a nightmare because my carers came at half 10 to get me up, which is what they do after the district nurse has been, and of course there was nothing they could do for me... they came. They made a coffee and tidied up, but other than that they were paid to do very little. #4

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- I'm quite lucky that on certain days – Mondays, Wednesdays and Fridays, the two carers that come don't have a job immediately afterwards, and so they'll phone me and say, 'has the district nurse been yet,' and sometimes I'll be like, 'no I'll phone you when she's here'. Then they'll head over knowing the district nurse will take 15 minutes...

So I'm quite lucky, but this morning both the carers that come for my 10:30 call have jobs at eleven thirty, so they do me 45 minutes and then they have a 15 minute window to get to their next client or whatever... What they don't seem to appreciate is that I was transferred into bed yesterday at four o'clock which is quite early, I would normally try and wait out until 8, and so I transferred at 4.

...the district nurses don't seem to see a problem with me staying in bed until 4:00 today, and that's 24 hours. And there are times when I'll have, as a result of the district nurses, 36 hours totally in bed, because that they've not come at the time that they said.

I can't jig around my carers to suit the district nurses, because my carers have got a schedule in place. Luckily today, the carers came at ten thirty and then and I phoned up my care agency, and they got two girls that are part of my package of five to come here at one o'clock or 1:30 so I could get out for you... not get up for you, but get up. Get up and have at least some of the day. Nothing worse when it's a lovely day, or you got something to do and you just sat in bed. The way your bed's laid out, and unfortunately my ability to sit up straight means I can't even go take the laptop to bed... I can only use the laptop when I'm in the other room. #4

- Yeah, they are coming late and I don't know how to give the medicine.

So, sometimes the nurses they come late and you need to have your medicine at 10 o'clock?

11o'clock. Before 9 o'clock... the people is busy.

So sometimes the nurses are not giving your medicine on time, is that right?

No.

Can you tell me why is that an issue, why is that difficult?

Actually, I do the medicine before 9, so I can [eat at] 12 o'clock. But the people give medicine at 11 o'clock, so how can you give the food at 12 o'clock because [my stomach is] full up? I got one medicine is 3 times, one morning, one afternoon, one evening. If she is giving medicine at 11 o'clock, so how can I take the 12 o'clock or 1 o'clock? You have to give 3 or 4 hour.

So you need 3 or 4 hours after the medicine to eat?

Yeah.

Is that right? So if they come too late, you can't eat on time?

That's the problem, nurse sometimes coming late.

How about your carers? Do your carers come on time?

No, carers are coming on time. #5

- Actually 2 nurses come with timetable, but 2 they coming too late sometimes, late too much. #5

- Sometimes if my carers... if, say it's 6 o'clock and I've got people around or I'm all right or I'm tired, I can call and say, 'look, can you come an hour later', and she'll tell me, 'yeah, that suits me' or she might say, 'actually, I can come a half an hour later', so we just communicate that way. #9

- But he was speaking to the doctor yesterday, [#12] was, and he was saying to the doctor yesterday, they does his insulin later on and the doctor said, 'no, you've got to do it all together'. You've got to take your tablets, then start your breakfast, then your insulin. You don't wait a couple of hours because obviously, they've given [him] his breakfast too early every morning...

Because I think it's all down to the nurse. All of a sudden, now the nurse doesn't do it, so now they might turn up at 10 o'clock in the morning, they might turn up 11 o'clock. I've even come home from work at 12 o'clock. And the needle is still sitting here, cause the nurse's aint turned up. #12

Timing, even down to minutes is vital (potentially the difference between major downside and not).

- I finish work at 12, and then the time the carer finishes is at 12, so by the time I get home, there's about 15, 20 minutes – depends if I need to get any shopping or not. And then you don't know what you're coming into. What he does... 15, 20 minutes... And you don't know what he's up to, especially when he's here on his own, he's in the shed, he's doing all this stuff in the shade. But he can't do it, we've got told to take all the electric tools away from him. My son's, they've hid them, but no, not him, he goes and finds them. It's only for his own safety. #12

People and their families are not necessarily good at identifying and communicating major risks.

- When I was home, I couldn't see properly. But, I didn't take notice that it's going to become blindness. But after the hospital they said to me I'm blind...

[Her daughter]: To be honest, I don't know if she was completely, because as I said, she was getting around, so I don't know if she had slight vision - obviously not clear, but a slight, slight vision. Because, as I said she was getting around, and she was doing washing up and cleaning and that. But obviously, probably after that now, as time's getting on, because the bump was quite big on her eye.

...

How long since you've been to church?

Oh wow. Years now, isn't it.

#6: 2 years.

Yeah, 2 years now.

#6: It was my sight. I couldn't see coming down the stairs. I used to ask one of my grans to go to church with me and help me to see up the stairs and come down the stairs... I reckon sometimes I fall down, so I stopped.

Yeah, your balance, mum, as well, wasn't 100%. #6

Chaos happens suddenly and drastically (before and while receiving care) – sudden change can alter a lot in someone's life.

- *How often would she see the doctor before going into the hospital (8 months prior)?*

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Touch wood, thank god, she was actually quite a healthy person you know, it's just recently all this started. She was actually quite healthy. She didn't really, to be honest, just as I said, recently.

How long has your mum had diabetes?

November. She might have had it before, but she didn't know.

OK, so this is all very new.

Yeah, as I said, she might have had it before, but she didn't know. It's only when she went in hospital and they tested. #6

- I had 2 in the morning and one in the evening, and the carers failed to notice an eight centimetre by five-centimetre pressure ulcer on my bum. So when that burst I was rushed into hospital and that was October of the year before last. As a result I've had to give up work... I had worked with my M.S. for twenty-three years.

... luckily the district nurse came to do something else on my legs or something, and said, oh my god – phoned an ambulance straight away.... I was so poorly, I was pretty much out of action until January. I was in hospital for a week or two, came home, but I was completely bed bound... I'm strong enough to do that sort of thing [she presses herself up from the wheelchair slightly], so they were pulling up my trousers or putting down my pyjamas or whatever from that position, and they claim not to have seen it. #4

- *What else happened because of the accidents?*

Then I have nothing to do – depend on government money. They give me money, on which I survive.

Were you working before then?

I had a business – 3 business. Grocery shop, fried chicken and mini-cab office.

...

Do you still have them?

No, due to accident, due to illness, the businesses closed. I lost money – lot of money lost. Money bring from my brother is from America – he send it to me. 200 thousand dollars. Nearly 140 thousand pounds, so I open 3 businesses. Businesses continue running nearly 13 staff working under, but when I was accident, I made an accident, then everything is ruined. #7

- They just left me all of a sudden. I was fine. Imagine one day you're walking around, all of a sudden, you've got a backache and that's at, you're paralyzed, boom - that's that, you can't do nothing. I didn't know how to loo, I didn't know how to eat, I didn't know how to do anything, so then my partner was around at that time, he was in prison, so I had the 24-hour care. Then all of a sudden, it was like, we can't fund it, we can't fund it, and then they just all left, and I didn't have a choice. #9

- *What was going on that made you want to up [your care]?*

Because he couldn't get out of bed in the morning.

So that was recently then?

Yeah, three or four months ago.

Was that quite drastic? How was that?

Yeah, it was drastic. He's saying, he can't get out of bed. And that's why I got in touch with the occupational health again and I said to get a bed that sits up like a chair...

So your mobility has reduced quite drastically in the last four or five months?

Yeah, big time, big time... He used to fall over, but he's falling over twice as much now, two or three times a day, because they shuffle with Parkinson's and his feet get stuck, and he's falling over. As I said, he's been down the stairs, he falls out of bed. I might be down here, he might be upstairs doing something in the bedroom. The next minute, smash. He's on the floor. #12

Doing what they say they will is really helpful – the hospital social worker was especially helpful.

- I think it's been helpful. The social worker at the hospital was really helpful, as she arranged it all. Everything she basically [said] it did happen and she said if I have any issues or ask her anything I can email, because she gave me her email or I can phone her. But yeah, she was really nice, and helpful as well.

You mentioned that everything she said has basically come true, what were a few of those things that she told you?

Well she said about the bed. She said about the other accessories with the bed. She said about the carers. Just how many times would I like them to come, and she's giving the times of when I want them to come - if they're suitable for me. And I said, 'yeah' and then that was it really. Then she just said... and she provided pads for mum as well – bed pads.... ... she arranged it all, to be honest. #6

I'm unsure about some of the logistics of the care plan and support, like how the finances are and will work regarding my care, the length, etc.

- *How much you have to pay versus how much the council has to pay?*

That I don't know because... you saying that, I've just got a form... yeah, a booklet, a booklet, I've just received a booklet. I've got to fill out, and it's got something to do with payment. So at the moment there's nothing finalised about it. I don't know, I suppose after that booklet, obviously they will tell me. I've got to fill it out. #6

- *Did the social worker at the hospital go over that at all about the schedule and how long the care will last...?*

She did mention something like that at some stage, but she didn't exactly say when that will happen. She did mention something that. #6

- *So she didn't come anymore after that time...*

No.

So did the office tell you that a new nurse was going to come, or what did they say?

No, they didn't say anything.

They didn't say anything at all? So you didn't know if a new nurse would come or not?

No. #5

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There are often unpaid carers involved, or there will be unpaid carers involved.

- I've got to do mum's shopping and pay her bills, et cetera, et cetera and I have to prepare the food now, I have to feed her. I have to wash the clothes. It's not a problem, because I did it for my kids anyways, so one more don't make no difference. But yeah, it's fine, it's fine, I don't have a problem with it. It's fine. I'm OK. #6

- *Are there other people you can go to who can help you find that information?*

My sister sometimes. She calls the solicitor.

What has your sister helped you with in the past, can you give me an example of?

So if I need anything, I tell my sister... she tell the people if you can help him like that, or how do I bring it my family here or how do I make my British passport. So you have to call the solicitor, talk to them... #5

- If I bring my wife... help me about something... help everything. Carer can't help with everything.

Sure, your carer can't help you with everything.

Yeah. They can't stay here with me. He comes 3 times, 4 times, they can't stay in the night-time. If I bring child and wife, then the people can look after me, because they stay with me in the house. If I need anything, they can help it. But... In the carer office, they can't give you 24 hour the people. #5

- The plan change is not possible. Two times a day, go outside two hours every day, and one hour for food. Night time, my daughter, she will arrange food, and she will give it to me. My medication plus food. #7

- *So you would want more space, and more space would allow for your son and daughter to live with you – why is that important that your daughter and son live here?*

They'll look after me. #7

- And then I have my partner – he helps me quite a lot. #9

- Or my sister. She lives in East Ham... she come to see me. She come to look at me... she be coming tomorrow. Every Tuesday she come here. #11

- I feel alright, I feel alright. The carers come and ask me if I feel alright, is there anything I want, do I want anything at the shop, I tell them. I give them the money to get it for me. Even the neighbour next door. She said to me, 'you want anything, don't be afraid to tell me, I'll get it'. They're very good to me, them. She brings me bread, eggs, all kinds of things she brings to me. She and her husband.

So you feel you have a good amount of support?

Yeah, I have support from all. I got support from neighbour, sister, carer and the nurse. #11

- ...oh, what it was, we're trying to move, right. Where my daughter lives at Harlow, and she said, oh, mom, she said, at least I'll be here to help and all that sort of stuff. #12

- *And is that the first time you had carers?*

I never have them in my life.

[family member]: He has always refused them, he has always wanted to do it himself normally.

I never have before carers.

Have they offered you carers previously?

[family member]: Yes, he has always declined. He has always wanted to be independent. And we had us helping, we're constantly helping, the whole family, we've got a big family. #13

- [family member]: Maybe, I don't know if my Aunty has, maybe my auntie because she's spoken to everyone hasn't she? Maybe one of the sisters. That's not our department to get involved in. Our aim is to look after them and make sure they've got food. This and that and they take care of everything else, the sisters...

Everyone's got their roles. So like on Saturday my mum comes - Saturday, my dad, my mum. We come Tuesdays and Saturdays. Everyone's got their days. Twice a week. Tomorrow his son's come. Sunday another son is coming. Monday is [his daughter's] coming... #13

My relationship to the spirit, god, the sacred, etc. is a meaningful part of the day (Eid = god in the food, sacrifice, devotion to god, etc.).

- Christian radio she listens to. Christian Radio – Premiere Radio she listens to... There's a guy who comes on after the news, at nine o'clock. After nine o'clock news he preaches basically the word of God and that's weekly - that's every day. And on a Sunday now, 8:00 in the morning there's a lady who comes on...

#6: Pam Rhodes, Pam Rhodes. She conducts the service [Songs of Praise – BBC].

Pam Rhodes – 8 o'clock on a Sunday morning.

What do you like about Pam?

#6: She's all right [smilling]. I'm used to her because when I used to go to church, I used to listen to the service...

Mum, why is it important to go to church?

#6: Because I believe. I believe in the Bible.

How do you feel when you listen to the shows on the radio now?

#6: All right, sometimes I know the hymns that they play and I sing to them... I know some of them that they have on the radio...

What's the feeling you have when you sing - do you feel happy...

#6: Happy. I'm accustomed to it. #6

- Tomorrow is Eid... this one for Qurbani. That is cow, lamb, god, Allah... #7

- You know like in my culture or my religion or my culture. It says you don't die as long as you owe somebody money. You don't die... and even if you die, you be sure that you put on your will that you owe... #8

- I listen to this spiritual radio – I'm a born-again Christian. That one's been going on for years now. Premier radio...

How long have you been a born-again Christian?

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Over 10 years now.

What made you decide that you wanted to...

Well I used to drink, smoke, all kind of things that was bad... womanise. Since I accept Christ, I live a Christian life. Before I was sick I used to go the church up the road here, and we had to leave there, so Wembley. So before it was closed... all the churches closed now, but before I was sick, I used to go to Wembley on Sundays. #11

- *When you go to church, what does that do for you?*

... church and pray... help you to live a decent and Christian life. That's what the church does. It's really good to me. It helps me a lot... even with my sickness. [ ] prayed for me, and all that and help me to where I am now.

How so, can you give me an example?

It helps me a great deal, because when you're a Christian, you don't do things that you normally would do, like gambling and things like that, you just live a Christian life and live Christ alone. #11

I've had to forego previous staples of my day and week because of my illness, and that has left me in a strange place. It's also meant giving up a lot (relationships, routine, etc.).

- I worked for 24 years until I stopped work. And that was an accountancy body, but I was working in the education function, so it was more education. But then over 25 years that's been my background, education, recruitment, and helping colleges deliver tuition through apprenticeship schemes. It's all right. It's a bit weird not working at the moment. #4

I am reminiscing on a sense of independence and autonomy, even though I know an old way is not necessarily possible/ may not be possible.

- *What kind of thing are you looking for?*

Well in an ideal world something that's only about 20 hours a week and I can wheel there, but that's sort of pipe dream in the sense that... #4

- *What are your thoughts around work - what would work mean for you right now?*

It would mean, for me, I would be earning a little bit, and not having to rely on any benefits. #4

- No, because you can't shower on the day that [carer's are] not coming, which I don't like bed baths and it just doesn't feel the same to me. I'm used to getting up in the morning and having a shower. #4

- It was going down - I mean before that I was able to drive, do whatever I feel like it. Now I can't even trust myself to go down from here to cross the road.

When did you stop driving?

A long time... 5 or 6 years. Since my eyes started going a little bit funny. #8

- *Is there anything that you feel like you need just generally in life right now that would help you?*

Well all I want in life is to get back to my normal health. Get back to the man I used to be.

What would that look like? How do you know that you would be your old self, the man you used to be?

Well it would be a great achievement for me... [indiscernible]... have to do things for you. It would mean a great deal to me.

You would have more of your independence – you wouldn't need help.

That's right, that's right.

What do you feel like you need to get to that place? What will help you get to that place?

Well I think the grace of god will help me to get there. It's hard when you're a big man, and you've got to depend on people to do things for you. That's more like kids do, innit? Well it's just one of them things.

Yeah. To know I used to do these things myself... [ ] do them things for me. But with the grace of god, I will get there. #11

- We tried to tell him, 'it's five o'clock in the morning, go back to bed'. The carer is going to be here, and I'm on my way to work. The carer will be here at seven, but he was down here. #12

Where you going? I want to go to the toilet. Well, I said, you got a pad on, do it and don't worry about it. No, no, no. I want to go toilet. So he goes to the toilet...

#12: If I can get to the toilet I'll go to the toilet. #12

- *It sounds like you can't move around.*

No, I can't. In the night, like a yo-yo, like a prison. I have to carry [the catheter], it's very heavy. #13

- *Does anyone else other than the nurse do your insulin shots? Someone in the family?*

No, no, no. Only the nurse.

And do you also do your own insulin shot?

I used to. I used to for 10 years.

And you stopped?

Why I stopped? He stopped me.

The nurse stopped you?

No, no, no not the nurse. The government. #13

- I don't like not being able to care for myself, and I don't like... this is me, I don't suffer fools gladly, and so having appointments and carers and nurses and doctors coming gets just... I'd rather not have it. Although they're all very lovely, I suppose that's just what happens. #4

I don't engage in community support outside of what is prescribed to me

- Yeah, I think it's been OK. I can't walk, I can't go out, there's not really much I need to know. They once tried to get me to go to that

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centre. I wasn't interested.

The Bromley by Bow Centre?

Yeah. They asked if I wanted to go there. I said, I don't.

Who asked you?

Someone from [my care agency], I think.

Are there other things they recommended or suggested for you?

No. #1

• Yeah, I don't know. There are a couple of charities that are run for disabled people by disabled people. I know there is one on the Isle of Dogs, or Canary Wharf. I don't know where else I would.

Have you engaged with any of those services or just any other kind of general community services?

No, not really... Other than that, I don't do anything community wise at all. I'm a bit rubbish. I don't think I can blame my M.S. for that, or my care for that. I've always been a bit like that. #4

Do nurses play by another standard?

• Yeah, so she fixed the medicine and.... but I didn't need those things. Now it was an emergency to check my diabetes since my body was shaking. I couldn't talk because I needed to check my diabetes.

When is this from?

2 weeks ago.

So you wanted for her to check your diabetes and not do the other tasks but she didn't do it?

No

Why?

I don't know. So I told her not to come.

Did she not come anymore after that?

No, she did not come anymore. #5

• So on Saturday they were very, very busy – the left me out. They didn't come to see me... the nurses. So I waited for them all day. When they came on Sunday they said they were very, very busy, they don't know what happened. I said, 'you have to know what happened, why was I missed out?' 'I'm so sorry, I'll look into it.' I said, 'I want to speak to the manager.' 'She's in a meeting.' I said, 'OK, but this needs to be documented – why did you miss me out?' When she came the following day, well 3 days later... I said, 'what happened on Saturday?' She went, 'what do you mean?' I said, 'I spoke with you remember? Nobody came.' 'Oh, yeah, yeah, I'm not sure what happened.' #9

• *Can you do the injection?*

Yeah, yeah. And then they said, 'well, we'll send a nurse around to you now'. I said, 'well, don't bother'. And the nurse turned up here at two o'clock...

And you did the injection for him?

Yeah, I said 'why you here?'... #12

• I think it's the [Royal] London Hospital, and then they get hold of the district nurses and then they phone back and the district nurses, and then they turn around and say, 'no, we can't get there at that time'. So what am I supposed to do?

They said that they can't regularly get there on time?

No, they used to, they used to be here no problem. Certain people that work there, we know what time they come, but it's not the same people. #12

Nurses (and carers) have been careless and seemingly incompetent – I need more professional assurance from them.

• I had 2 in the morning and one in the evening, and the carers failed to notice an eight centimetre by five-centimetre pressure ulcer on my bum. So when that burst I was rushed into hospital and that was October of the year before last. As a result I've had to give up work... I had worked with my M.S. for twenty-three years. #4

• *What's generally been your experience like with the nurses?*

Very bad, very bad, because the sores... I went to hospital three times with sepsis. They failed to notice that the sore was so bad. #9

• Because nurses will come in and say, 'what dressings are we using?' And then there's all these names that you've got to remember. And thank God. I remember and I know, because if I don't know, the nurses will [indiscernible] different types of dressings. So sometimes like the sore will get really bad and start smelling, so I know we're heading for an infection, so I'm going to ask, 'is the [ ] there?' And then they'll say 'yes', and I'll have to say, 'can you use silver?' because I know that lifts it. Now if I don't tell them that, they'll just stick on whatever, you know, just to cover it up. So I kind of have to tell them use this, use that. I can't see my back. I can't see the sore, I can just smell it and I can just tell, and then, so they listen to my instructions. Whereas I would rather they tell me, and then I will feel a lot better. #9

• I can't see my back. I can't see the sore, I can just smell it and I can just tell, and then, so they listen to my instructions. Whereas I would rather they tell me, and then I will feel a lot better.

Your sense is that they don't fully understand the challenge around the wound?

No, no. Maybe a one or two of them. So, someone might come for a week and not notice, and all of a sudden someone's going to come, and say, 'oh my God, call the ambulance, call the doctor. And then I've been like this for over a week. I've been like this for two weeks. So nursing, yeah, I would say, very bad. #9

• I'm sick and I want to feel like they're professionals and they know what they're doing, and I'm in good hands. Not me having to tell them. And I'm just like the blind leading the blind. I just have to go by what... from experience.

I don't know. Sometimes I want them to tell me, if I tell them, look, use Silver, I want them to tell me, 'no, you can't because of this'. But they wouldn't. 'Oh you want to use that, OK'. And I could be wrong. Maybe Silver is not the right thing. Once I was using Silver all of the month, but we realized we can't use it for over two weeks. You've got to stop. They were just slapping it on, slapping it on. Then the manager came one day, she had to cover, and was like, 'oh, you do know Silver only we use it for two weeks'. I didn't know that. #9

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- Well some are proper dedicated nurses, some they don't know what they're doing half of the time. Couple of the [ ]… they're in and out in about two minutes… they're short staffed at the moment… Well it depends on what nurse I get…

They've not always got their mind on the job, and I think quite a few of them are not 100% qualified, but they could be students, you know what I mean.

What makes you think that? What have you seen or heard…

Because they don't seem to be concentrating properly on their job… There are good nurses. I know they've got a hard job, but some just don't seem to properly care as much as they should do, you know what I mean, which doesn't help. #10

- The Botox stopped, and then they give him drops to go under his tongue, but the drops under his tongue, if they didn't go under the tongue, they hallucinate him, big time. The district nurses done it, but they put it on the tongue, so I come home from work and he was really, really bad, hallucinating, had to come off of them straight away, because that was down to the nurses. #12

- So on the Tuesday she comes, [#12] rough, really bad, couldn't sit up, couldn't open his eyes. And she started really shouting and him, and I thought, well you're a nurse? I'm here and I'm listening to it. What else are you doing to these other people? Do you know what I mean – who's got nobody there. 'Sit up, sit up', she's pushing him back up. Sit up, sit up! I said, 'what are you doing?' I said, 'leave him alone'. 'No, no, no. He's got to sit up'. I said, 'leave him alone, he's not well'. 'We'll get an ambulance then.' The way she spoke was unbelievable… So phoned the doctor's, had a really bad water infection, and that's what caused it… A water infection, a really bad water infection. #12

I have to be 'on the ball' and diligent about my health situation, otherwise I may die from my care

- I don't think I would be here today if I didn't watch my back.

Cause nurses will come in and say, 'what dressings are we using?' And then there's all these names that you've got to remember. And thank God. I remember and I know, because if I don't know, the nurses will [indiscernible] different types of dressings. So sometimes like the sore will get really bad and start smelling, so I know we're heading for an infection, so I'm going to ask, 'is the [ ] there?' And then they'll say 'yes', and I'll have to say, 'can you use silver?' because I know that lifts it. Now if I don't tell them that, they'll just stick on whatever, you know, just to cover it up. #9

- In the first two or three minutes you can just tell what you're dealing with. And then you have to point everything out. 'Oh, and by the way, can you used this, oh.' 'Oh by the way, the scissors… you know they're cutting something and putting it into my wound. And the scissor just on top of the table, so I have to tell them, 'oh by the way, can you disinfect the scissors', and having to watch. It's meant to be disposable scissors, but they don't get the scissors, and then they're running around trying to find scissors, and there are scissors all over the room, cause they use it and just leave it there. So I trusted them, I used to think they're disinfected, but I came close to death one to many times to know not to trust them. #9

I can call the care provider when I need something logistical regarding my care

- *What do you usually call them for?*

By phone – any problem or anything like that.

Can you give me an example of when you've had to call the office?

Last time asking I need, suppose tomorrow, I'm going to my kid's house, my daughter's house. So after Eid tomorrow then 3 days after I'll be back, so these three days, I don't need, I don't want service, because my kids, they'll look after me. So again, I tell them Monday morning to start again. #7

- With the carers really. I don't have much contact with the agency, cause I've got no issues, no complaints and if I do I just tell the carer. But if I do have complaints, there is… so I've got 2 numbers for the care agency where I can speak to them directly… I've asked her to come on and so hopefully, they said she can apply, and then they'll just keep an eye out for her application (she's driving hiring decisions), and hopefully try and… cause she knows my ways as well. She worked with me quite a while back. She's quite good, and we've stayed in contact.

I literally just spoke with them about that a couple of hours ago. #9

I need repairs done and/or I'd like a new living arrangement – this is directly linked to my care (e.g., children living with me).

- Plus this, my door problem – broken. You can have a look. Smashed, so they are coming one day, and 3 days booked with me, they are working here.

Before 3 days ago, leaking in the bathroom – the floor to here. This type of condition, not working properly.

So if you have a problem like this – the leak or the door, who do you speak to?

I speak with the council – request to them please, repair it. Otherwise, you send someone in the area who will look at it first, and he will see what's going on, and what to do. #7

- *Any other specific things you want to share?*

I need another house, because this flat is very old. My daughter she joined me already in this flat. She live with here, not regularly, because the [indiscernible] no good, plus problem in this room [indiscernible] very small, so I need two, three bedroom house – I want if it is arrangement for housing people to talk to you, then in future my daughter and my son, school teacher, and my daughter, they are buying.

So you would want more space, and more space would allow for your son and daughter to live with you – why is that important that your daughter and son live here?

They'll look after me. They'll look after me. #7

- We're trying to move, right. Where my daughter lives at Harlow, and she said, oh, mom, she said, at least I'll be here to help and all that sort of stuff… They provided everything they can provide, a stair lift, we've got, we've got a walk-in shower – a wet room. They given all this… he's got a hospital bed, and all that. So there's no more that they can do, so it doesn't matter where we live. #12

I'm turning inward, and disconnecting from society | my world is shrinking.

- As long as the cat's got enough food and I got food, what the heck do I need? Nothing else.

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So you feel pretty content as long as you've got some food and the cat's got food?

Yeah, as long as I got food, cigarettes, I'm fine... the rest of the world can go around me. #8

- Yeah. In the afternoon, I can shut my door, and leave everything in the world behind, but he doesn't turn up, so he doesn't turn up. #8

- Now I can't even trust myself to go down from here to cross the road. #8

I don't want to inconvenience my care – it's hard for me to receive

- And she would ring me up every day... 'how you doing?' 'Oh, I'm doing all right'. Because even if I'm not doing all right, I would say that - you know why? Because I don't want to spoil her day. My day is lousy. Why should I bother spoiling her day? #8

I don't like/ trust carers that are indifferent and/or absent (physically, emotionally, etc.)

- *What's your sense around why they are not so diligent about the sores?*

I think they're busy – they're busy, they're not bothered, they're just doing their job. It's not all of them, but most of them. So 7 out of 10. So I'm just doing it for the sake of doing it. And the other three are basically doing it and keeping us alive, because they genuinely care. #9

- I mean even the last [carer]... to try and accommodate him, to say, come in certain days, but Friday you come in for the two hours he's supposed to clean up. Come in, do a bit, go to the mosque, and the Tesco next to the mosque, and do a little bit of shopping for me, and then go, whatever.

Are you joking? You know what he would do? He come in for about two minutes, and before I know it, he's gone. Would I see him again? Not bloody likely. So why am I paying. #8

- I can just tell if someone is in to their job, and really wants to kind of help, or if someone is just doing it for the sake of doing it... I noticed actually, earlier on, my carers gone on holiday, so they wanted to send cover, and she came before, but I just didn't like her attitude, because sometimes she's in a good mood and sometimes she's in a funny mood for no apparent reason, so I just told them, I don't want her. #9

I had to build a familiarity with my condition – it takes time and failure

- That time it was the urine, so that time the care just stopped. I had no sores, but I think urine infection I had. At that time, it was still all new, I didn't know temperature, I didn't know feeling thirsty, I didn't know the signs. #9

- Yeah, trial and error. So I've really been through it all now, so now we know how to help ourselves. #9

I feel like I'm struggling/ fighting to get the care and trust that I need/ deserve.

- Now I've told them that till I'm blue in the face, and nothing. It's a headache. From the moment I wake up, it's a fight and battle. #9

- The thing is, I don't want to fight. I want care, that's all. I'm British, I'm entitled to care, and that's all I want, and I'm having to fight for that... we have a nice health care, but the nurses are not doing what they're getting paid to do...

...I shouldn't have to pay for private care when the NHS should be doing it anyways. I'm not asking them to do anything special for me... It's my life, it's serious. #9

- I said to the people over there. I been to England in 1959, I come here. Yeah, 1959 I come here to this country. I never been to the police station, I never been arrested for anything, I never have any trouble. Who's proof do you want? These people [ ]. I proved to these people, I said, 'who do you want to believe? Me or these people?' He doesn't answer, nothing.

Right, so your thought was that you've contributed a lot and you haven't been an issue in this country.

I haven't done any trouble – Cyprus and here. Including... I'm here now.

And you don't think the [care agency] believes you?

No, they don't believe me. If you give another job to the same people, they don't believe you. #13

I've diabetes, and changing my diet and lifestyle is a real challenge – it's deeply emotional and psychological.

- Because every other day I'm cheating with the diabetes. Which is silly, but thank god it's been on an even keel, and it was good this morning, only 7.5, which is very good, but I spoil myself nearly every day, which is silly.

Yeah, I eat sweet things that I shouldn't eat. The depression gives me a sweet tooth, but I just got to have will power, and I haven't got very much will power at the moment, cause I got a bad cold, and I'm just so badly run down.

I take it out on myself, which is silly. #10

- Yeah, by eating sweets, which is silly. Very silly. Because I know the consequences, what can happen. I mean, my father was also diabetic. Before he died he lost both of his legs. He wasn't looking after himself, and he went blind, so my eyesight is not that good, but unfortunately, I haven't got enough willpower. #10

- I have a dentist... trying to get myself some false teeth, because I probably be able to eat a lot better... I lost most of [my teeth] due to the diabetes. #10

- Well I can talk to district nurses – they wouldn't want to listen, but it's mostly myself that should do this. It's 99%, I just got to tell myself, I got to keep off of sugar. I'm sure I could, but I got to have the willpower, because the way I'm going at the moment aint careful... I could accidentally overdo it and go into a coma. I'm such an idiot. I'm my own worst enemy. I do it for comfort, which is not comfort in the end. Because I'm slowly but surely going blind, you know that... God forbid I go blind, that'd be the end of it. All I need is to go blind. #10

- With eating, I try to keep to a sugar-free and fat-free diet, but it's just when I get out the snacks I go out and buy...

Have you spoken to anyone about the diet?

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I have, a few years ago – the doctors, they gave me a diet sheet, but I just didn't take notice of it properly. If I let people help me more, it would help me. My mother was the same… She wouldn't let people help her… her pride I suppose. #10

- Well as I said, the church was up the road, I passed there one day, and a woman stopped me, and she said to me, 'do you go to church?' I said, 'no'. She said, 'there's a very nice church, you must come.' And I said, 'I'll try'. I went to try, and from that, that's where I get baptised and everything there.

Why did you decide to try it, what were you thinking?

Well I was thinking nothing special, I only think that I have somewhere to go, because I stopped going in the pub and all them places, so I said, well alright, a better place is the church. #11

- *What made you want to stop drinking?*

When I was living in East Ham with my sister, and when I come down here, the doctor in East Ham, he said, it's best you get a doctor near your home, because if anything happens… and I went down there, Chrisp Street, and the first morning I went there, they interview me, and they said to me, do you smoke, I said yeah, do you drink, I said yeah. And he said to me 'how much', and I said 'quite a lot'. The nurse said to me, 'would you like to stop drinking?' And I said, yeah, I would like to stop drinking and smoking, so she said, 'when?' I said, well, I like it to happen now.

So what she do, she give me some inserts [gestures toward his mouth] to take when I feel I want to smoke, so she give me some, and I bring them home. I start to take them, and then I take them back out there, and I said, look I don't want these no more. You better give them to somebody that really need them. And that from day up to today, I haven't smoked or drink. #11

- So I feel it's only will power that make people smoke.

Now, you feel you've got some will power – what does the will power help you do in the day?

I got the will power that I aint got to do the things that is bad, or is not good for my health… if something isn't good for me, I won't have it. #11

- We had the physio about two years ago to do exercises with his mouth – couldn't do it, and they said that would stop it, or try and stop it, but no, again. Then, same as his back, where he's like 90% over, and they told him that, **gave him all exercises to do – [he] wouldn't do it**. #12

- He's been in coma twice over his sugar level.

#12: …mornings where it's been 6.8 spot on. Can't get no better than that…

So are you generally pretty good about keeping your blood sugar…

No, he isn't. [#12's] got a very sweet tooth. He can eat a tub of ice cream. He can eat a packet of chocolate, he can eat packets of biscuits, you name it, he can eat it. #12

- Coma. Twice.

He was in the garden… about three year ago. It was in the garden – he was fine, puttering around, nice day… he wasn't nowhere near what he is now. Just sitting in the garden doing stuff. And I looked at him, and I thought, oh, he's asleep. He was leaning on the table, he's asleep. Left him there, he was in a coma. I couldn't wake him up. Right in to intensive care. His sugar level just dropped. #12

- Me and [my primary carer], we cook together now. She showed me how to cook a curry and things, so it's quite nice. Cause I watch her cook what she does, and that, and we enjoy cooking together.

Is that particular thing important - cooking together?

Yeah, because I can see her cooking, I can see what she's doing, so I know she's not poison me or anything like that.

What is it about cooking together that that you find meaningful?

Cause I'm learning as well, you know, because before I didn't know how to cook a curry. I just used to get curry jars, but now I learned how to cook one, I can cook and it last me a few days. It's something fresh, and that, it's not something you stick in a microwave. So it's nice and fresh, it's got fresh chicken, potatoes, mushrooms and chickpeas. And it's really nice. Instead of having microwave meals, it's really nice.

So cooking and food is an important thing for you?

Yeah, I have to be careful because of my diabetes. I have to be careful, like the sugar content, the salt content and all that carbohydrate, so you have to be careful, and I have to be careful about my weight as well. #3

I've experienced intense trauma, and/or need psychological support.

- But I haven't had a good life, really. I was raped by my own father years ago, which doesn't help… And I worshiped that person.

It's made my nerves very bad, because of my own father. I'll never get over that, I think…

Have you been able to speak to anyone about that – the abuse?

I have, yeah, but I haven't got very far. I don't need to see a psychiatrist, because with the help from [my carer]… #10

- I'm a peculiar person. Good thing I can laugh because at the moment I'm so depressed…

Are you able to communicate that to your carer?

Yeah, and I'm on antidepressants, but I'm so immune to them. They don't do much for me. If I didn't have my partner, my friend and my carer, I might as well say goodbye.

I know I shouldn't talk like that, but I'm just… I haven't got enough proper faith in myself, which is stupid. #10

We have a major risk to the downside, with little insurance and/or coordinated plan around it.

- I can't pick him up, and he always sits on the floor or tries to get up off the floor. I've tried and half the time there's nobody in the house, only me, and I can't do it. And obviously I try my hardest to get him up. #12

- He used to fall over, but he's falling over twice as much now, two or three times a day, because they shuffle with Parkinson's and his feet get stuck, and he's falling over. As I said, he's been down the stairs, he falls out of bed. I might be down here, he might be upstairs doing something in the bedroom. The next minute,

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smash. He's on the floor.

What do you do then after 12:00, after the carer leaves - if he falls, what do you do?

#12: I have to try and get me self up.

Well, we have to try and get... the frame, he's got one upstairs. I have to try and get that around him, try and get him around, so he can try and get up himself onto the edge of the bed if there's nobody else in the house, or if my son's here or anybody else is here, I give them a shout and they come and try and pick him up. Obviously, I can't. #12

The level of support from the council is not sufficient for dignified care, and paying out of pocket is not possible.

• It's hard, because they only supply two pull-ups a day, the council. And two pull-ups a day is not good with anybody like [him]. We've tried and tried and they said, no, you can have the normal pads, but he can't put them on. And obviously, he thinks it's degrading by anybody helping him putting them on, so he can't use them. So I'll pay for it. They give you eight packets, last for three months - the pads. They're obviously... he gets a bit of diarrhoea, so we're having to go out and buy the pads. They're not cheap, they're like 12 quid for like 8 pads. #12

I have assumptions and expectations about how things should be done that are different from the carer – these expectations are non-linear (e.g., I may smoke in the house, but may want towels washed after one use).

• And other things that are really petty, but I don't like people washing up because I think that... and particularly my carers, are awful at washing up, it's disgusting. I can't bear it. It's not a critical thing, because I just say, 'don't wash up' and so it doesn't annoy me, because they don't do a bad job, because I don't let them do that job. #4

• Like face [towels], I got about 30 face [towels]. You use a face [towel] once, you wash it. Use a towel you washed #12 in the shower – dried, that's dirty. In my eyes that towels dirty... no, he hangs the towel over the edge of the bed. He can use that tomorrow, I went, 'no, it's dirty. He's used it once, that is it...

Yeah, like I only use a bath towel once. I don't know how many times other people use it. Face [towels], I only use it once. #12

• OK, so what I'm hearing then is that you've told him that you want things done a certain way around hygiene and cleaning...

Yeah, obviously that's my... it's the way I grew up. #12

• I take my phone to work, but obviously it's on silent, I can't have it ringing at work. They've got my work number - if you want to speak to me phone through work, and that's fine, but not on my personal phone. #12

• [family member]: He's just lost his trust in people.

Yeah what are they supposed to be doing? What do you understand the carers' jobs to be?

You find good people, but also bad people...

When I working is my thing, he working the same thing as these people.

[family member]: he wants them to work the way he used to work. #13