



Supporting Carers in Southwark: continuing the dialogue

Event report

February 2020

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Introduction

‘Supporting Carers in Southwark: continuing the dialogue’ was an event organised by Healthwatch Southwark on 19 February 2020, to launch our report [‘The Impact of Caring on Unpaid Carers’](#) and further build on our relationship with local unpaid carers. The event was well attended by 27 unpaid carers, as well as ten representatives from organisations that support carers, four members of staff from Southwark Council, six from Community Southwark, and five from Healthwatch Southwark (including one volunteer).

This launch event was an opportunity to share the findings of Healthwatch Southwark’s engagement with carers, and whether find out whether they resonated. We also wanted to give carers the opportunity to be listened to directly and connect with other local carers, so we can continue the dialogue between services and service users. We were pleased to welcome staff from the Adult Social Care department of Southwark Council to our event, to build on our collaborative relationship, and give them the opportunity to listen and chat to carers in an informal setting.

The event was structured in three stages: an opportunity to network and look at stalls from a variety of support organisations; presentations from Healthwatch Southwark and Southwark Council; and table discussions.

Stalls

Several organisations that support carers in Southwark hosted stalls to provide information and chat to carers. We welcomed representatives from Citizen’s Advice Southwark, Southwark Wellbeing Hub, AgeUK Lewisham & Southwark, Alzheimer’s Society, and the Southwark Dementia Action Alliance.

Presentations

Catherine Negus, Manager of Healthwatch Southwark, welcomed the attendees and introduced the purpose and activities of Healthwatch Southwark. She explained that Healthwatch had chosen unpaid carers as a priority area based on issues raised by local people, and because unpaid carers might not always get the chance to be heard, due to the pressures they faced.

Simon Rayner, Assistant Director of Adult Social Care and chair of the Council’s Carers Board, then gave a brief information session on the current and future support offer for carers in Southwark. He spoke about two future Hubs, for Older People and Carers and All Age Disability and Carers, and highlighted the 2

importance of getting support right before carers even have a formal assessment. He also detailed the work the Council was doing on the Carers Pathway and Joint Strategic Needs Assessment of the local carer population. We were especially pleased to hear plans to co-design a Carers Protocol with carers, to implement best practice across the Council, and for a working group to improve Carers Assessment. Simon noted the importance of the voluntary sector in supporting carers, and how 80% of Council funding is channelled through the voluntary sector. Dora Felkai, Commissioning Manager, then spoke about the Southwark Carer Awards being organised for 2020, and encouraged attendees to nominate paid and unpaid carers.

Catherine then gave a brief presentation on our report, [‘The Impact of Caring on Unpaid Carers’](#), including the methodology and key findings. She highlighted the importance of qualitative research - finding out about people’s experiences and the meanings behind them - to service design and implementation.

Table discussions

We held two roundtable discussions at the event, with a mix of unpaid carers, organisation representatives, and Southwark Council staff at each table. A member of staff from Healthwatch or Community Southwark facilitated the discussions, with another to take notes. The first discussion was themed around Challenges, and the second around Resilience. Our goal was to find out more about what would enable carers to continue in their roles without detriment to their own wellbeing. We wanted to build on our report findings about the resources that carers find most useful, and consider how we might prevent protective factors from being eroded.

We asked:

- **Challenges**
 - What makes it more difficult to be a carer?
- **Resilience**
 - What makes you, or would make you, feel:
 - Supported
 - Well
 - More able to care and keep caring?
 - What would help you to build or keep these things in your life?

We analysed the notes from the table discussions and grouped things inductively into themes. Across the discussions, we found that these broadly fitted with the main themes we found in our [research](#) (pages 5-6). A few carers also told us at the start of the discussions that the report “resonated” with them, or that they “identified with the findings”. Others wanted to know more about the health conditions of the carers themselves, and spoke of the need to maintain momentum and translate the findings into action.

The table discussions build on our report in several ways. Hearing the recurring themes that prompted the most group agreement and elaboration allows us to reflect on our findings, and adjust the aims of our ongoing work accordingly. We can also explore the relationships between different themes - for example, how one 'challenge' might influence another. Finally, we can understand more about the kind of support carers want, and how to get there.

The information we gathered from the table discussions is presented in two ways: grouped into the themes we identified, and in a visual map to show the potential relationships between different themes.

Challenges

Knowledge

Some carers felt they lacked knowledge or training in some areas, such as power of attorney, mental health first aid, or the cared for person's illness. Carers also felt their jobs were harder when health and social care professionals lacked knowledge of their cared for person's condition and how this could influence their behaviour, especially dementia. One person said their cared for person with Alzheimer's might resist or refuse help due to their condition, but this would be accepted without question by social workers or paid carers. Someone else felt that care home professionals did not appreciate how much physical activity someone with dementia, especially early onset, needed.

Coordination

Carers found it challenging when support and communication was uncoordinated. This could be at transition points, for example from child to adult services or into care homes. One person said there was a "disconnect" when their cared for person went into a nursing home, and they stopped receiving information. Someone else shared concerns about the new Hubs in the borough, questioning whether people would "fall through the gaps" - they were unsure, for example, whether someone with dementia would go to the Older Persons Hub. Others shared how they took on coordination themselves. They were the advocate, and sometimes "every step [was] a fight".

Communication

Some people struggled to get through to their GP or to Southwark Council, or said that responses could be delayed. Not knowing what to do in these situations made them feel uncertain. A few carers had been told things by social workers that made them feel frustrated or like their concerns weren't being taken seriously - for example that they weren't in crisis. Some carers felt services were not listening. It was seen as crucial that services be tailored to each carer or family, and no assumptions should be made about what would best relieve their burden. A few people discussed how, in the other direction, service offers needed to be communicated more clearly - especially the difference between signposting, advice and support. Some had found out about useful support, such as training or transport services, only by chance or late in the day.

Time

Carers felt their time was limited for a variety of reasons. They had to spend time waiting around for inefficient patient transport, accompanying the cared for person, or managing their own health condition when they weren't caring. This meant they had less time available for their hobbies and activities, which could lead to social isolation. One person also shared their experience of "24/7 care", and how they had to be alert at night. This constant alertness could contribute to chronic anxiety and sleeplessness.

Challenges

Inconsistency

Many carers highlighted inconsistency as a challenge in different ways. For example, the high turnover of paid carers, or repeatedly seeing new social workers that did not seem to know their situation. Sometimes paid carers or sitting services would be late or not turn up, which had knock-on effects - for example, one cared for person wasn't able to go to school. A few people felt the burden on paid carers needed to be reduced and regulated, so they could provide continuity and spend more time with the cared for person. Carers were also concerned about the consistency of services, as they were aware of general funding cuts in the sector. Lack of continuity and the resulting lack of personalisation could sometimes result in services (such as paid carers) increasing rather than decreasing the burden on unpaid carers.

Anxiety

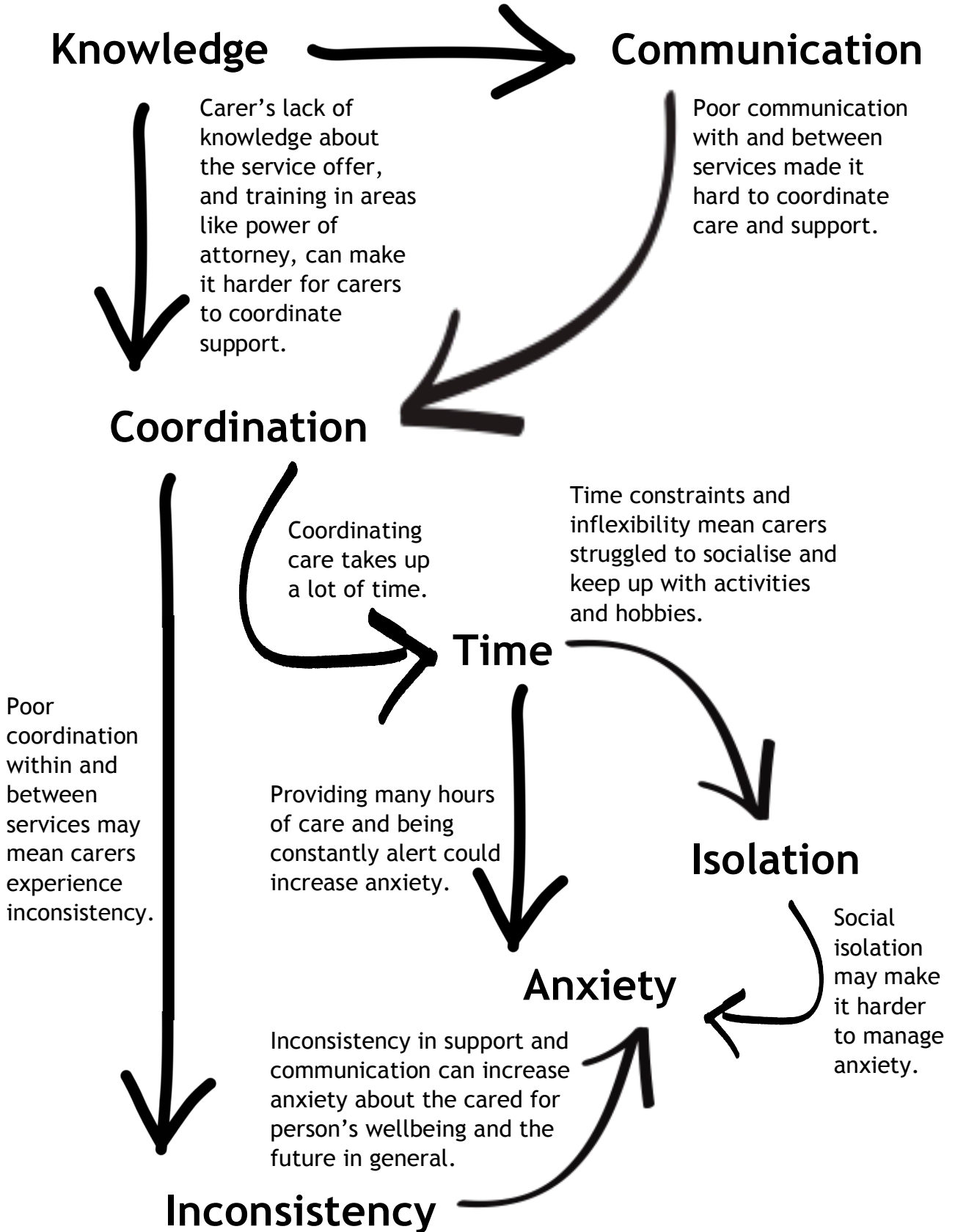
Carers shared the anxiety they felt for the health and wellbeing of their cared for person, describing it as having "no peace of mind". Some felt they couldn't plan for the future. Others mentioned the fear they felt waiting for the outcomes of assessments or reviews, and the lack of control associated with not knowing when it would come, or whether the care package would be cut. They said you "just had to wait for a letter in the post". Anxiety meant they struggled to switch off, to go to sleep or to make the best of respite. Carers spoke about how they tried to self-manage anxiety and the other psychological impacts of care; for one carer, this was because of the long waiting times for Talking Therapies.

Isolation

Carers discussed how being isolated made it harder to care. Some people said their relationships with family had deteriorated, and that family members could leave the 'caring' all to one person. Others said they had drifted away from their friends, as they didn't want to be a burden. Caring meant they had lost autonomy and flexibility to socialise on their terms - and some friends didn't 'get it' when they cancelled last minute.

Challenges

Staff may lack knowledge about the carer's situation and cared for person's condition can contribute to poor communication.



Resilience

Services

The carers discussed a broad range of services they felt did help or would help them feel supported, well and able to care. These were:

1. **Drop-in support** sessions at the Hubs.
2. **Alternative therapies** such as massage, acupuncture and reflexology.
3. **Activities** they could attend with their cared for person, including outings to museums or galleries.
4. **Advocacy**, so carers could have more involvement and control in assessment and review processes.
5. **Counselling** (with a reasonably short waiting list and flexible timings).
6. **Day centres** for the cared for person.
7. **Wellbeing activities** such as singing, mindfulness, dancing and cooking.
8. **Transport**, such as a community minicab service.

Training

Lack of training came up as a challenge for carers, so they wanted this gap to be addressed in themselves and in the professionals they encountered. Carers wanted training in:

1. **Self-care.**
2. **Compartmentalisation and time-management** (to manage the division of caring and 'me time').
3. **Mental health first aid.**
4. **The conditions and disabilities** their cared for people might have.

They wanted professionals to have more training in:

1. **Empathy and listening skills.**
2. **Dementia awareness** and working with someone with dementia.

Respite

Respite was highly valued, and carers wanted access to a few different types of respite, that had different purposes. These were:

1. **Respite alone** for a break from caring. A few carers also said that this should factor in preparation and travel times.
2. **Respite with their cared for people**, to have a supported holiday.
3. **Sitting services** (ideally including night-sitting and flexible sitting at short notice).
4. **Crisis respite** for urgent or last minute situations.

Information/education

A few people said they wanted to see more **education of the general public** about their cared for people's conditions, as "people get isolated because the public lack understanding". Carers themselves wanted to be **informed** about being a carer, the support available to them, statutory services and processes, financial management, and managing mental and physical health. It was suggested this could be in a **booklet or handbook** given to them at their first point of contact with a service.

Resilience

Reliability and security

Many carers spoke about wanting “peace of mind” and to feel “less under threat”. They felt could be achieved by:

1. **Regular assessments.**
2. **Consistent communication** through a clear channel, such as a key worker.
3. **Secure funding** for support organisations for a specified period.
4. **Better staff inductions** and measures to **reduce staff turnover.**
5. **Having an emergency plan** in place in case they were suddenly unable to care.
6. **Advocacy** during assessment and review processes.
7. **More advanced planning.**

Holistic approach

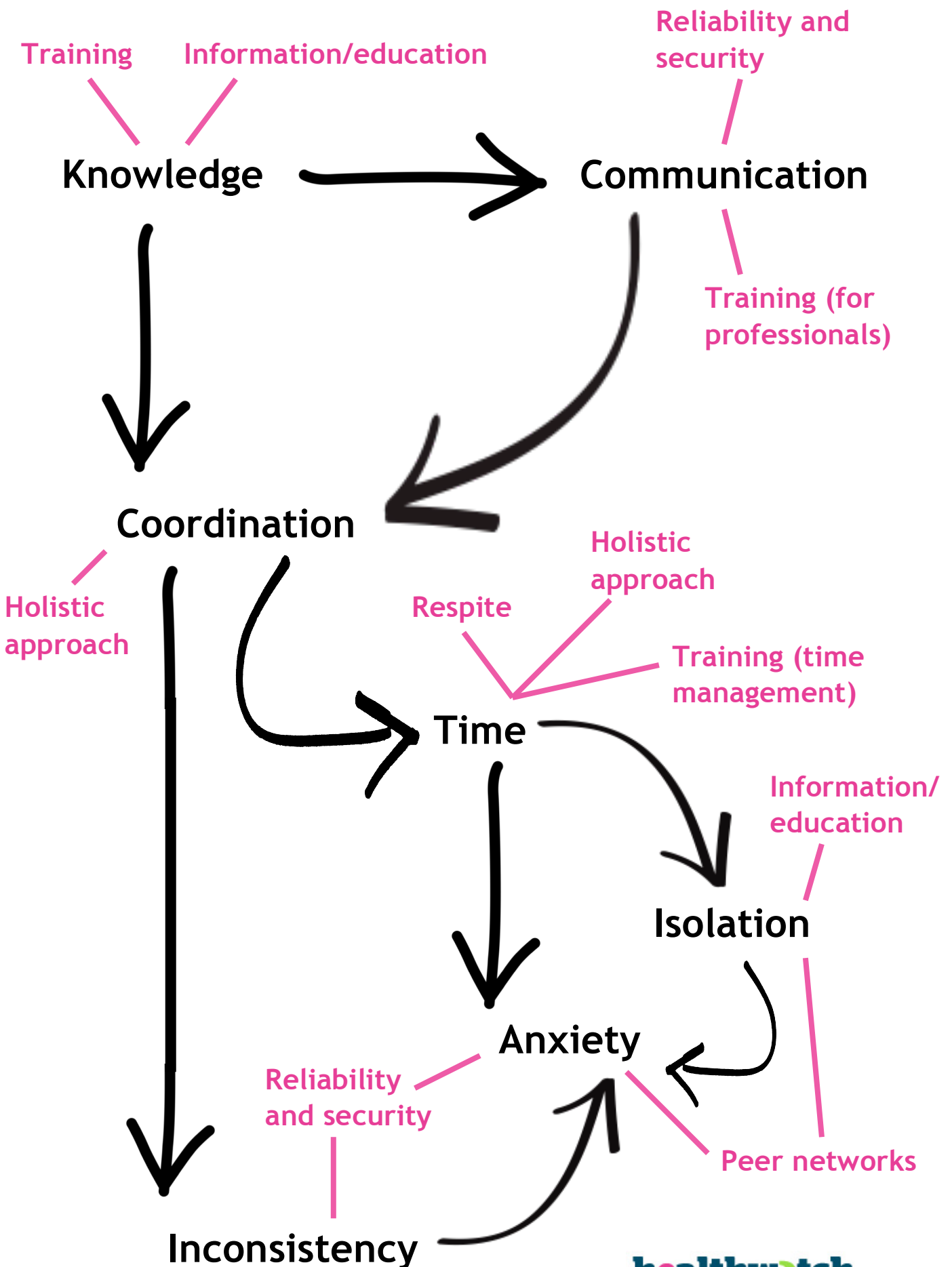
Carers wanted to see more holistic and interconnected coordination for their, and their cared for person’s, support. They suggested this could be achieved through:

1. **A holistic assessment** process like Safe and Independent Living (SAIL) provided by AgeUK.
2. **Social workers** located at GP surgeries to provide advice and support.
3. **GPs acting as coordinators** for carers’ support, by being aware their patient is a carer and then signposting them to all the support services.

Peer networks

A few carers appreciated the on-going support their local church gave them, saying “it saved me when I really needed it”, and wanted **faith leaders to be educated** more about mental and physical health conditions and disabilities. This could help faith groups identify hidden carers and understand cared for issues better. Others mentioned contact with their **neighbours** or just “**keeping in touch with reality**” by going for quick daily walks as a source of resilience. Some carers wanted **peer groups** to share information, signpost one another, and provide **friendships** that could “replace those lost to caring”.

Resilience: protecting against the challenges



Event evaluations

24 people completed an evaluation form. We asked attendees to rate different aspects of the event, and the event as a whole. **92% of attendees described the event as good or excellent.**

- **92%** of attendees thought the presentations were good or excellent
- **79%** thought the stalls were good or excellent
- **88%** thought the table discussions were good or excellent
- **96%** thought the venue or location was good or excellent
- **92%** thought the food and refreshments were good or excellent
- No one described any aspect of the event as 'Poor' or 'Very poor'.

We also asked attendees to agree or disagree with several statements about the event¹.

- **71%** agreed or strongly agreed that they knew more about the work of Healthwatch Southwark
- **67%** agreed or strongly agreed that they knew more about the work of organisations that support carers
- **79%** agreed or strongly agreed that they got the chance to connect with other carers
- **83%** agreed or strongly agreed that they got to chance to share their views

We also gave attendees the chance to comment on what they liked about the event, and what they thought could be improved.

Over half of people said they liked **sharing their experience, connecting and listening to other carers** during the table discussions.

- 'Fantastic table discussions with lots of relevant action points.'
- 'The chance to hear and exchange experience'
- '[I] felt that we have been listened to and that the information will be put into action.'

Five people said they liked the **information** given at the event, by the presentations and stalls. A few others complimented Healthwatch Southwark on the '**calibre of work in progress**', and said that they felt we 'genuinely wanted to hear and learn what is important to carers'.

The main thing people would have improved was **making the event longer**, so they had more time for the discussions: 'Need more time to say all. Want to scream shout let all out!'. Two people would have liked the event to be at a **different time**, for example outside of working hours. Finally, three people would have liked the **CCG** to be at the event (they were invited, but did not attend) and one person said we should have invited some **GPs, nurses, or practice managers**.

¹ Two people marked 'strongly disagree' for all statements, but rated the event very positively. We therefore excluded them from the analysis as they may have mistaken 'strongly disagree' for 'strongly agree'.

We asked attendees what future events they would like Healthwatch Southwark to organise. Four people said more of the same, for example an **annual event for carers**. Two people suggested practical **training** for carers.

Equality and diversity monitoring

19 people completed equality and diversity monitoring forms.

Age	Number
50-59	5
60-69	7
70+	2
No response	5

Gender	Number
Female	14
Male	2
No response	3

Sexuality	Number
Heterosexual/straight	16
Lesbian	1
No response	2

Ethnicity	Number
White: English/Welsh/Scottish/Northern Irish/British	8
Black or Black British: African	3
Black or Black British: Caribbean	2
Black or Black British: Colombian	1
Asian or Asian British: Chinese	1
Asian or Asian British: Iranian	1
Other: African Caribbean British	1
No answer	2

Religion	Number
No particular religion	7
Christian	7
Muslim	1
Atheist	1
Other philosophical belief: Bahá'í	1
Prefer not to say	1
No answer	1

Day-to-day activities limited by a health problem or disability	Number
Yes, a little	2
Yes, a lot	4
No	9
Prefer not to say	2
No answer	2

Type of impact	Number
Physical	2
Sensory	1
Mental health	1
Long-standing illness	1
Learning disability	1

Carer	Number
Yes	11
No	2
Other: home sharer	1
Prefer not to say	1
No answer	4

Cared for person	Number
Parent	4
Partner/spouse	2
Child with special needs	1
Friend	3
Other family member	3
Other: young adult	1
No answer	6