# The Realities of Hospital Discharge

Kensington & Chelsea age UK

*Conversations with people living with dementia and unpaid carers on their recent experiences of the hospital discharge process in Kensington and Chelsea*

# Contents

# 01 Introduction

*I think there is much more scope for humanity*
Michael, living with dementia

How and when people are discharged from hospital matters; it probably matters even more for people living with dementia and their unpaid carers. People living with dementia often experience longer and more frequent hospital stays, delays in leaving hospital and reduced independent living.[1]

Over a six-month period, our researcher has conducted over 25 interviews with 10 people either living with dementia or the unpaid carer of someone living with dementia.[2] This research report is based on and amplifies the recent first-hand hospital discharge experiences as told by participants themselves, as well as what the first few months post-discharge was like for them in Kensington and Chelsea.

This research report follows the timeline of the hospital discharge process; providing direct quotes of the reported challenges faced by participants,[3] as well as what made a positive difference for them and recommendations going forward. **With this research, we hope to contribute to:**

- An in-depth understanding of the discharge/post-discharge experience of people living with dementia and their unpaid carers
- Identifying any gaps in provision to inform future commissioning decisions
- Creating and maintaining a safe space for participants' voices to be heard
- Kensington & Chelsea becoming a more dementia friendly borough

Over the course of conducting this research, 4 out of 10 participants experienced re-hospitalisations (3 people living with dementia and 1 unpaid carer managing their loved one's hospitalisation.) This emphasises just how important listening to their voices and experiences is to bring about change.

The researcher recognises the significance of this subject and her responsibility in conveying the voices and stories of participants, who are often in vulnerable positions.

Accompanying this report is a supplemental Audio Story. Audio versions of relevant quotes throughout the report can be listened and referred to here so the voices of participants can be heard: **Realities of Hospital Discharge - Audio Story**

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[1] - Hospital care | NICE impact dementia | Reviewing the impact of our guidance | Measuring the use of NICE guidance | Into practice | What we do | About | NICE

[2] - For more detail, see Appendix 1: Methodology

[3] - 'Participants' refers to all participants in this study, including both unpaid carers and people living with dementia

# 02 Key Findings

*I felt very disorientated. I didn't know what the time was, I didn't have my mobile phone, I felt very cut off*
*Hannah, living with dementia*

## 1. Lack of a Joined-Up Approach

If we take the challenges with the hospital discharge experience as a whole in this research, it can be best encapsulated as a series of communication break downs at all levels. Structural issues lie at the heart of this and contribute to fragmented working relationships between primary care, secondary care, community care and/or tertiary care. The lack of a joined-up approach in this way undoubtably contributes to hospital re-admission as effective support is not provided and unfortunately, this allows people to easily fall through the gaps.

***...as a family that you're learning about the importance of keeping things as stable as possible and then seeing medical teams doing the opposite of what the recommendation is. It kind of feels counter-intuitive and then you end up with somewhere that's kind of the step change and they've been pushed back even further in their health. So yes that would be really good to see if that could be a bit more joined up. –*** Danielle, unpaid carer

**Ineffective, dis-jointed and/or non-existent communication in all aspects of the hospital discharge process is the most overarching and prevalent grievance expressed by participants in this study. (70%)**

## 2. Lack of a Person-Centred Approach

Poor communication directly inhibits person-centred care. Unfortunately, this report highlights many examples of basic failings in the approach towards and treatment of people living with dementia and their unpaid carers. This is evident even at the beginning of the hospital experience where some participants were left feeling isolated and disorientated on the ward itself. However, communication breakdowns were ever-present at all stages including at the point of discharge and in the months post-discharge.

Many participants felt disregarded, uninformed, and distressed due to absent or detrimental communication. Unpaid carers also noted that professionals often lacked interest in understanding the specific and complex needs of their loved ones. Unfortunately, this inattentiveness and lack of a person-centered approach can increase the likelihood of hospital readmission, as crucial information for ongoing care may be omitted or overlooked.

***I think that...when the social workers are prepping care, [they should].. learn more about the individual....Like what are your likes, dislikes, a bit about you, your background, that's useful as well I think for the social worker to maybe gather that information to share with the care provider so they've got an overview of what she was like beforehand –*** Danielle, unpaid carer

## 3. Inconsistency

There are examples of great support in this borough, however the gap between positive and negative quality of care experiences for some participants in this study was vast. This inconsistency was a feature of all aspects of the discharge process; between different hospital experiences, different care organisations and the quality of support from professionals both in hospital and across different services. The baseline experience for people in this borough should be more stable and this reflects a need to really prioritise and incorporate dementia-specialised support, training and funding to ensure that good quality experiences don't feel like an anomaly.

***I mean I nearly fell over when the first time my brother said to me, "My God they've been here 45 minutes. They are talking to mum as a person, they're dealing with her irritation and they're not getting rattled. They've cleaned up after them," etc, etc and it was like music to my ears but why should it be like that? –*** Patricia, unpaid carer

In addition, although there are existing dementia services in this borough, there seems to be a general lack of awareness surrounding them. In part, this is due to those services only receiving short term and inconsistent funding which leads to unreliable and outdated community support mapping. It is important that these services and organisations are supported enough in terms of resource and capacity so that these issues can be resolved.[4]

The importance of longer-term, sustainable and inclusive community support is highlighted here. As Chris, one participant living with dementia put it - ***'It's too many stops and starts. So you don't know where you are starting, where you are stopping. And can you, can you find a place where you can say that's interesting. What they are doing there's a certain amount of value but you have to also constantly be aware that you cannot stop and start.'***

**Small and creative changes related to communication and practical support to access services could make a huge difference to people living with dementia and their unpaid carers. Changes of this nature would not require huge structural upheaval; even small steps can make a substantial impact.**

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[4] - See Appendix 2: Community Mapping for more details regarding future projects to close this gap

# 03 Hospital Discharge Timeline: Challenges

## i. Isolating Hospital Stays

For many people living with dementia and their unpaid carers, the nature of the hospital stay itself plays a key role in the eventual discharge process. If the hospital stay exacerbates the symptoms of dementia and/or cognitive decline, this in turn can negatively influence hospital discharge and lead to potential re-hospitalisation.

During this research, two unpaid carers noted that the person they cared for was under-stimulated on the ward. One unpaid carer expressed that the lack of communication and subsequent isolation of her loved one was a setback for her health.

***...the space is just, just would not recommend putting someone with dementia in a room on their own with no stimulation. It's just, yes, it's quite cruel.... And if we weren't visiting there's, even the door opening, it just caused a lot of paranoia of, "Oh they're talking to me," Or, "This person's talking" and someone with dementia and delirium at the same time, she felt she was being punished. She told me she was in jail...*** – Danielle, unpaid carer

One person living with dementia was put in a ward with no daylight or windows. Their unpaid carer pointed out that they needed to be able to:

***...actually see outside and not feel cut off from the world, as already feeling cut off from themselves, and then physically cut off, it's just not helpful.***
 - Danielle, unpaid carer

If we take into account the importance of 'Social Interaction' in Appendix 3: Key Dementia Facts, we can see how damaging this is for someone living with dementia.

***It wasn't clear to me where the medical people were taking me and where I was going. And I felt basically neglected. I felt rather lonely*** - Michael, living with dementia

### ii. Poor Preparation for Discharge

**Most participants (60%) expressed a common sentiment – they lacked sufficient time to review essential discharge information. Additionally, some reported not receiving any discharge notes or communication about next steps.**

***I thought at least they could spend five to 10 minutes just sort of saying here's the discharge letter do you want to have a quick read or do you want them to just go through that with you? None of that ever happened. I find that a bit odd. –*** Trish, *unpaid carer*

Some participants stated that medical personnel seemed rushed and overstretched and that the face-to-face interactions were extremely limited and aloof. They noted that being disregarded in this way was a difficult and isolating experience to be faced with.

***I was constantly checking with the doctor and trying to find out what was happening when and I didn't get anywhere. To be fair it was very, very compromised on staff ...and she was very good, but she was obviously managing a huge caseload.***

**–** Trish, unpaid carer

***My husband has a profound hearing loss although he may or may not have his hearing aids in, but even if he has them in he still doesn't hear very well... if somebody's at the end of a bed and they're perhaps usually talking to their computer screen and occasionally go, is that okay? You know, and back to the computer screen he's not really getting any interaction.***

– Trish, unpaid carer

There was a shared feeling between all of the unpaid carers during the interviews that in many instances, medical information concerning their loved ones was something to be sought after, and not freely given. Some of this group described feeling as though they were chasing hospital staff around trying to get basic information surrounding the discharge process, medication and timelines. Some noted that they felt like a nuisance or a burden to over-stretched staff.

It is important to note here that some participants living with dementia felt as though they would be extremely vulnerable if they didn't have their unpaid carer to support them. Without their unpaid carers coordinating and managing this process (often at the expense of carers' well-being), they felt as though they would struggle.

***Researcher:*** *How would you feel if someone was like yourself but didn't have the support of your wife (unpaid carer) here to help them?*

***I'd know they are in trouble–*** *Chris, living with dementia*

### iii. 'Medical Jargon'

For those who did receive discharge notes, 40% of participants expressed that the medical terminology used in their hospital discharge notes was unintelligible and not explained to them by medical professionals. This meant that they were googling and researching what terms meant and what particular diagnoses were. Some noted that the use of 'medical jargon' without explanation was particularly alienating and confronting especially as they were not medically trained. This led to some participants feeling as though they were being discharged and left to their own devices.

***So then I looked at the discharge paper and when I read it I thought, Oh gosh. So I Googled, you know, a number of the- And I didn't know then what troponins- I'm not so sure if I'm even pronouncing them properly were***

- Trish, unpaid carer

### iv. Poor Dementia-Informed Communication

An unpaid carer interviewed noted that medical personnel didn't talk to the person living with dementia in her care, but only directed their speech and gaze to communicate with her. This caused the person in her care to feel infantilised and excluded from decisions surrounding her medications and discharge.

*What I do notice that when you say that someone's got dementia, the assumption is we don't need to talk to them or just talk to the family because they won't know what's going on. [but that is not the case] she knows what's- She's very aware. But the explanations around what medications you're taking and what they're for and why...... should be ... clear, so people are aware. They might not know but at least you've given them the information so they're fully informed about what they're taking. Mum questioned every tablet that was going into her because she was a healthcare assistant before in her life. And so she was like,* ***"Well I want to know what I'm taking. I don't want to just take a load of tablets. And actually I'm not going to because no one's telling me what they're for."***

– Danielle, unpaid carer

However, another unpaid carer noted that the person living with dementia in her care had incorrectly communicated that her son would be picking her up in his car from hospital. This participant noted the frustration she felt that family members were not consulted to clarify how the person in their care would be transported from hospital.

***So lunch time comes, I phoned my brother and said, "Is mum home?" "No." "Have you checked it? Have you chased it up?" "No." "Well is she having lunch at home or what?" you know. So time went on. Just after lunch he received a phone call from one of the nurses saying, "Are you coming to pick up your mother?" and he said, "No I don't drive," So of course that then meant there was a whole well you know panic about getting transport sorted. End result she wasn't brought home that day, it was the next day. Now if someone with knowledge of dementia on the ward or even without that knowledge had phoned my brother and said, "Can I just check that you are coming to pick up your mother today?" then it wouldn't have been a problem.***

– Patricia, unpaid carer

This highlights the importance of a person-centred, informed and nuanced approach to communication when people living with dementia are being discharged from hospital.

### v. Unplanned Discharges

One person living with dementia (accompanied by unpaid carer) reported that they were not told to make preparations to go home and that this decision happened abruptly without explanation. This made things unnecessarily more difficult especially for the unpaid carer who was trying to manage the pressures of these logistical demands at short notice whilst also feeling that their loved one was not well enough to leave hospital and should stay longer.

***…then I said, "Well how is he going to get home?" And she said, "Well you're in the discharge centre for him to have transport." I said, "Because he hasn't got any clothes with him it's raining outside and he hasn't got any shoes. If I had known he was going to be discharged I would have brought those things with me."*** – Trish, unpaid carer

***On the Wednesday I was called by the ward doctor… I couldn't really understand what he was saying, but he said he was ready for discharge. So I said, "Oh okay, where is his care package?" And he said, "He doesn't need a care package," and I said, "Oh really? That strikes me as being rather odd," and I said, "Because have you taken into account all the things that are wrong with him?" …. So he said, "Oh," and obviously he hadn't looked at the record and my husband was just saying to him, "I'm fine, I'm fine, I'm fine," because he obviously wants to get out, "I'm fine," to everything.***

– Trish, unpaid carer

### vi. Lack of Coordination

Once the patient is discharged from their hospital bed, they are taken to a discharge bay where they await a discharge social worker coordinating their discharge and care package assessment. This includes picking up the correct medication to take home. Unfortunately, the majority of participants stated that delays in timings and logistics occurred throughout the whole process of discharge.

***I think it was the medication, there was the delays, but I think everyone communicated very badly because they'd say to me, oh, you're going home today and then someone else would say, no, you're not today, you're going tomorrow, and it went on all week. I didn't know whether I was coming or going.* –** Hannah, living with dementia

Some unpaid carers noted that they would be waiting hours at a time in the discharge bay. Either transport had not been arranged or was either arranged whilst other cogs of the discharge process had not starting turning; for example, transport being on hold as medication had not been delivered to the pharmacy.

In one instance, a patient was discharged from their hospital bed prematurely, only to encounter lengthy waiting times in the discharge bay. Both an unpaid caregiver and an individual living with dementia observed that this experience was unnecessarily disorienting and emotionally distressing.

*It's a miserable experience. You don't know what's going to happen...you don't know where you're going to be, and* ***it's just the vicious cycle constantly going round and round and round. And I don't know how to get off that circle, the hamster on the drum, I don't know how to get off it****, because as soon as I think, Oh we're doing well, and then we go down again. And I just constantly go round and round on the spinning wheel and I don't know how to get off it. Because as soon as I try to step back, suddenly we go downhill again.* – Trish, unpaid carer

**During this time, it is crucial that there is a joined-up approach between the hospital, medication delivery and transportation to ensure an effective and efficient discharge. However, for 70% of participants this has not been the case and this particularly impacts people living with dementia.**

# 04 Readjusting to Homelife: Challenges

## i. Premature Discharge

Readjusting to homelife after a hospital admission can be an isolating and confusing time for people living with dementia. However, during the course of this research project, it was really the unpaid carers interviewed who expressed intense areas of challenge they faced whilst being the advocate for and co-ordinator of their loved ones' care.

***They gave her a drip and her levels increased and then she was sent home. And then two days later went back in for the same thing. So it was clear that she was discharged too early. It felt a very rushed process. We didn't engage with the doctors on that process at all really. So it was kind of like she's fixed, she can go home, she's better to how she was - and that wasn't the case. -*** Danielle, unpaid carer

Three unpaid carers interviewed noted that they felt as though their loved ones were not 'medically fit' for discharge and were discharged too early. This was unfortunately demonstrated in both cases by the person in each of their respective care being re-hospitalised shortly after.

***I would have liked him to stay longer but they insisted to send him back home after two, three days stay. So when he came back he had a fall from the bed. He couldn't do anything.... it was more dangerous because I didn't know how to treat him. If he could have stayed two or three days longer until the brain is more back to normal, I really appreciated that.***

- Madhu, unpaid carer of participant suffering with a UTI

### ii. Discharged with No Care Package

After every hospitalisation, care packages should be re-assessed and reviewed. It is vital that the right questions are asked and thorough assessments conducted. However, half of the unpaid carers interviewed reported not being offered a care package and/or reablement[5] or having any type of discharge/care assessment at all. They detailed the subsequent struggle of re-adjusting to homelife; both feeling ill-equipped to deal with the complexities and the emotional toll of their loved one's condition.

***Again I asked, "Where was the care package?" And they said, "There isn't a care package." So I said, "Well where is he going to be discharged to?" And they said, "Wherever," they didn't seem to know. So I said, "Well there's only me and I can't look after him. I'm also elderly*** - Trish, unpaid carer

***Everything was just new and I didn't know how to cope***

- Madhu, unpaid carer

Some would call their GPs, attempt to call social workers (If they had their contact details), or other organisations. However, they would experience extended waiting times and no call-backs. They very much felt the absence of one single person who was managing their care and frequently did not know who to call for a particular request.

***The team that contacted us the most was occupational health so to make sure that mum's set up at home was good, so that when she returned and so what was she was able to do. But those were the ones that engaged with us the most rather than the actual doctors telling us kind of what was going on and how the discharge process would work. So when she was discharged we had a social worker come up with a care plan. She was allowed the six weeks of initial care that you can get. But again we were given no social worker contact.***

- Danielle, unpaid carer

### iii. Post-Discharge Disorganisation

Even for those who had a period of reablement, the post-discharge period was still an incredibly challenging time. Half of all participants expressed the lack of a single point of contact to speak to in organising theirs or their loved one's care during this period of transition.[6]

**All unpaid carers expressed elements of confusion surrounding how community, secondary and primary care organisations worked together, which organisations were responsible for what, who to contact and when, and what support they were entitled to.**

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[5] - Royal Borough of Kensington and Chelsea. (2024, March 22). Support available in your home

[6] - It is worth noting here that the residents in extra care facilities struggled less with post-discharge disorganisation. See section 05 "What Worked?" for more details

***It's different services, different teams, different budgets, all the rest of it, but it doesn't make it the smooth running that you need it to be, especially when someone's-She's still not 100%, and she's still adjusting to being back home, so you want those things to go smoothly for her.*** - Danielle, unpaid carer

Similarly a significant number of unpaid carers noted instances of ineffective communication between care agencies and the person in their care in which the agency worker didn't speak to the person directly, or patronised them using infantilising language, or asked personal questions too early without establishing familiarity or trust with the person living with dementia. This contributed to unpaid carers managing emotional and fraught responses to this and in some cases, large setbacks in the recovery of the person living with dementia as they would not want to engage.

***...of course you get inconsistency and delays. Delays in calls being returned, in medication being administered, mixed messages and that.....we've had the pharmacist calling us from the surgery and asking us about why medication was being changed or issued and I'm thinking here we go again. Why are you not talking to somebody in the surgery? What's on the notes? Is there anything on my mum's notes?***

- Patricia, unpaid carer

### iii. Post-Discharge Care Agencies

***The process was very rushed and therefore there was a lot of back and forth afterwards where we're kind of trying to find out if she had a social worker. But she didn't. [we were then following up with the care agency about when their care was finishing. [We] didn't get any support with that until it just stopped kind of suddenly, the care that she was given. So we then had to find our own carer to come in to play. So yes, so that whole process was just very, very disjointed, very stressful.***

- Danielle, unpaid carer

Two unpaid carers spoke about the disorganisation of care agencies booking time slots to come over and either not turning up or turning up at different times altogether. They also noted excessive waiting times before care was put in place. One unpaid carer mentioned in a recent discharge that carers had turned up unexpectedly without any advanced notice. She noted that when this happened, she had to step in to provide emotional support to explain to the person living with dementia why there were unexpected, unknown strangers in her home.

In a similar vein concerning communication, unpaid carers interviewed noted instances of ineffective communication between various care agencies and the person in their care. These included, again, not speaking to the person directly or infantilising them with patronising language. It also included asking very personal and affronting questions too early without establishing familiarity[7] or trust with the person living with dementia. This contributed to unpaid carers managing the, oftentimes, emotional and fraught responses to this and in some cases, large setbacks in the recovery of the person living with dementia as they would not want to engage.

> ***For someone that's a bit confused of what's going on as it is, it just felt very inappropriate for them, they didn't call before they were coming to say we're going to be coming to do this, they literally just rocked up to the door, to the point it was like, "I'm not comfortable telling you my financial situation. Please can you leave." Because that wasn't, we weren't told. If someone tells us we're going to- Every other service has called up to say "Hi I'm this person, we're going to come and see your mum. Is it appropriate? Will you be there? Would you like to be there?"***
>
> - Danielle, unpaid carer

Half of unpaid carers interviewed also noted the vast differences between differing care agencies in the quality of the care received. When a particular carer or agency did not meet quality of care standards the burden and frustration of managing this was challenging.

### iv. Post-Discharge Equipment Issues

Another avenue that proved a challenge was the delivery of necessary equipment for recovery to the participants' homes. In this particular study, items included a grab rail, a walking frame and the re-positioning of a hospital bed. Three participants spoke of delayed delivery of these items and not being able to get in touch with the organisation providing the equipment, as they had no contact number.

They also spoke about issues surrounding the arrival of items. Items were not correctly fitted or they were delivered without instructions on how they should be used. One unpaid carer noted that this could have resulted in another fall as her loved one attempted to use a walker, without training, so she had to step in. Another unpaid carer spoke about furniture that should have been moved to prevent a fall, which wasn't. One person living with dementia spoke about an item being delivered and left without their opinion or any consultation of how it should be set up. This led to a hospital bed being delivered and installed at an angle that could increase likelihood of falls.

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[7] - See Appendix 3: Key Dementia Facts

*They just put it up and that was it. I said, "I can't even get between that to get in the wardrobe, I'll get myself stuck… It just wants turning around, that's all. So, I don't know when they're coming.*

– Maude, living with dementia

Sadly, all of these small details add up to an increased likelihood of hospital re-admission and unnecessary hardships for the participants who experience them.

### v. Fragmented & Temporary Support

The sustainability of voluntary and community sector services was also raised as an issue for some participants. For example, you may be signposted to various organisations and projects, but these may only be funded for a short space of time, subject to refreshment assessments and/or are in constant flux.

For the majority of those interviewed, their most recent hospital stay was just one of many hospitalisations over a number of months or even years. This has meant that some of these funded but time-restricted support options have already been utilised and expended for them. For example, limited sessions and/or referrals for certain projects. Not having consistency in this way leads to instability in terms of on-going support.

In addition, if going to community groups isn't appropriate for an individual living with dementia, due to the advanced stage or type of condition, there is a shortage of personalised one to one support options available in comparison with the rising need. This means that due to limited capacity, some people living with dementia in this borough are not getting enough person-centred support that would be genuinely beneficial. This can have a detrimental knock-on effect for re-hospitalisation rates.

All of the issues listed above leave us with people, including those featured in this study, who feel they have limited tangible support options (other than private resources) for a terminal condition with complex comorbidities.

### vi. Administrative Fatigue

All unpaid carers interviewed shared a sense of administrative fatigue from coordinating the care of their loved ones and navigating the fragmentation of the system itself. Following a hospital discharge, as outlined above in this report, they expressed the sheer weight of constantly liaising with multidisciplinary organisations, finding new services, waiting and following up on phone calls and emails, repeating themselves, overseeing care and/or equipment delivery and problem solving to be completely overwhelming.

*Now I don't know how that could have been better at any level but the pressure of people phoning, the physios, the social worker, discharge social worker, the staff on the ward, I mean it really was a lot but we achieved it and mum got home before Christmas, excellent and all the rest of it but the discharge process on that was just horrendous.*

– Patricia, unpaid carer

In addition to this, one participant described the constant cycle of assessments, re-assessments, referrals, surveys and funding assessments for care to be so overwhelming that these tasks for her have become triggering.

***I feel like I am being grated. You know you grate your cheese to pop on your meal or whatever I just feel like I'm being grated away. There's another little bit of grating, there's another bit, chip it away. You know it feels endless and on top of that we're losing our mum. We're losing her.***

– Patricia, unpaid carer

Another participant expressed feelings of complete exhaustion, apathy and being at her wit's end.

### vii. Financial Pressures

One of the participants mentioned that they had recently managed to pay a private carer using funds that the person under their care had fortunately set aside. The alternative for those without this option are assessments and questionnaires to determine whether you fit the financial criteria for funded and/or subsidised support. One participant commented that working out what services or benefits they were entitled to was complex, stressful and information surrounding this was not freely given.

On a similar note, one participant noted that the carer's allowance received is incredibly low, especially for someone who gives round the clock care and is therefore not able to work full-time. For her family, this means that the 'fight' to get more funded/subsidised care is currently increasing. This comes with its own difficulties as mentioned in the previous section on administrative fatigue.

*I shudder to think how I would have managed if I was working but then again it gets to the point where you just have to. Either your mother suffers, the individual suffers or you … and you can live with that and not get bothered about it or you are bothered about it and* ***you just keep stretching like an elastic band.***

– Patricia, unpaid carer

### viii. Health of Unpaid Carers

It is impossible to understate just how important the health of unpaid carers is, especially when in many cases, the unpaid carer is elderly themselves. This is reflected in this research with 75% of unpaid carers interviewed being sixty or over.

All unpaid carers during the course of this research spoke about the mental and/or physical health challenges that they are currently facing. **The value of unpaid care in this country is equivalent to a second NHS in England and Wales**[8]; if unpaid carers are not looked after and supported, it can have further ramifications on the person living with dementia's care.

One unpaid carer spoke about the recent physical manifestations of the stress she was under through caring for her loved one, which included hives and rashes.

***It's stressful. I'm just getting the antihistamine tablets from GP. I went yesterday because I started getting itchy all over. And she told me that is from the stress***

– Madhu, unpaid carer

Another spoke about mental health conditions that had been exasperated such as anxiety and recently, one of her siblings existing health disorders, hypervigilance, has been intensified due to the current strains of caring for their parent. Hypervigilance is a serious health condition usually associated with war veterans.

***I know what hypervigilance is and what anxiety does to people and he hears my mum calling him night and day even when he's out on his day off or he's popped across the road to do some shopping he hears her calling him. He said it's like she's sitting on my shoulder and this stems from being awake frequently, well for the last four years or so with mum calling him during the night***

– Patricia, unpaid carer

Other damaging health ramifications expressed during this research have included sleep deprivation, issues with substance addiction and recent progressions of osteoporosis due to the strain of a loved one living with dementia being consistently hospitalised and discharged.

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8 - Key facts and figures | Carers UK

## i. Kindness and Human Connection

When things went well for participants throughout the hospital discharge experience, key points they noted were the very human stories of moments of kindness and connection in the hospital experience itself.  When some participants living with dementia recounted stories of their hospital stay, they fondly recalled nice conversations with people and staff who were kind and connected with them.

***Some of the people were very nice that I met…when I was having my x-ray a man asked me my name, and my date of birth and everything, and he said to me, "You're exactly the same age as my mother and she's got a birthday in March too". And so, he was very nice.***

- Hannah, living with dementia

Others noted how individual professionals in various services across Kensington and Chelsea went above and beyond to help, advise, and check up on them. One particular participant noted the importance of a healthcare professional taking a holistic approach and really taking into account the totality of her mum's symptoms and treating her as a complex individual pre-discharge. She felt listened to and supported. These acts of connection, kindness and individual professionalism were noted as truly positive highlights in the hospital experience.

***The nurses there are really good. Their dementia team came to her as well because she was on an older, elderly care ward. So they came and visited her or did the kind of questions, tell me about, like everything about her, made efforts to kind of- She wasn't drinking water from the hospital so they bought a bottle of water in a bottle so that she could open it herself, just to help her with getting hydrated and being more trusting of things around. So they were really good.***

- Danielle, unpaid carer

***They are keeping us abreast of how she's getting on. They do two ward rounds a week. Which we're involved in as well. So they do call up to update us as to what they'd like to do. We went in for the care plan I guess, the meeting to see - The treatment plan. And very much wanted to do that in support with us so we knew what was going on. And also it has helped us when we spoke to mum to know, to tell her and relay the same information to her. So we're all coming from the same place. So they've been really, really good.***

- Danielle, unpaid carer

### ii. Good Support at the Point of Discharge

One participant recalled a recent discharge where there was a volunteer in the discharge bay who was incredibly attentive, asking if they wanted any help with discharge and had any questions. This was particularly noted as a rare, positive experience.

This highlights the importance of person-centred assistance and information sharing at the critical moment of discharge.

***...it was the volunteer actually she was a volunteer, but she happened to be a nurse and had not so long ago lost her own husband and so she said, "Would you like me to-" I said, "I don't even know what this discharge paper what- I don't know any of the technical terms in it." And she said, "Would you like me to go through it with you?" I said, "That would be very kind thank you."***

- Trish, unpaid carer

### iii. Good Post-Discharge Support

Half of unpaid carers expressed the difference it made when, post-discharge, relevant professionals had enough time to spend with the person with dementia, were well-trained and prioritised a person-centred approach. This also meant that they were trusted by the person living with dementia and were able to pick up on any issues effectively, preventing re-hospitalisation.

***...physically they pick up on issues a lot quicker. Like mum had a pressure sore developing, they were on it and contacted the district nurses directly. So what their system is they pick up on issues, they email it into the office and then the office contacts the relevant medical person.***

- Patricia, unpaid carer

In addition, three unpaid carers noted the difference it made when a particular professional had specific dementia training and awareness. Although this will be touched on more in section 07: Recommendations, it is important to note that these participants felt that the quality of care, good staff-training and specialised communication skills had radiating positive effects for not only patient outcomes, but also for the unpaid carers themselves as they felt supported and looked after.

### iv. Good Post-Discharge Services

Some participants spoke about how beneficial some of the services on offer in this borough had been for them. Some of those services are mentioned in the Appendix 2: Community Mapping. When some participants had access to services such as My Care My Way & the Age UK Dementia Advisor, they felt listened to, supported and one unpaid carer noted that it felt like the pressure on her had been eased. This was especially true when the professionals had a level of clinical training.

***The one good thing that came out of the back of it though was the care, the support we got from My Care My Way team. They have been really good following up, trying to find out- So trying to find out social worker contacts for us on our behalf. So that was really, really- like that team provide a really good service I think.***

– Danielle, unpaid carer

***Having the support of the Admiral Nurse has been really, really good. And also my sister lives in Harrow, she cannot access the services here. But there is the general Admiral Nurses number as well so she has been calling up, just to get advice and information as well. Which has been really, really good.***

– Danielle, unpaid carer

***So learning about the memory cafés and all the stuff locally that she's been provided with has been really good. So I had information sent to me, the team when you do call are really, really good at just picking up the phone and just talking to you. And very understanding about what you're doing as well.***
– Danielle, unpaid carer

Some participants also noted the role that the services and activities they were part of played in increasing the person in their care's overall well-being and brightness. In one particular case, an unpaid carer said that it made her ***'heart so warm'*** to watch her spouse engage with a dance class at Resonate Arts.

Similarly, one participant living with dementia noted that the Age UK Kensington and Chelsea's Exercise for the Mind class in her extra care facility was something she was enjoying as part of her recovery after a fall:

***...And I've started going to a new exercise class, it's on Tuesday afternoon, and it's just up the corridor on the left. And it's a new man that taken over and we all enjoyed it.***
– Hannah, living with dementia

### v. Authentic Post-Discharge Communication

Two unpaid carers spoke about the importance of authentic and clear communication in order to manage expectations post-discharge. There was a shared understanding that the system itself isn't perfect, but that it is better to be informed than to be left in the dark.

Even when the news was frustrating or not what they had hoped for, honest and empathetic communications surrounding this helped to manage expectations and to foster a shared understanding. One unpaid carer stressed that although things can and do wrong in the hospital discharge process, if this was effectively and genuinely communicated to them that really made a difference. She noted a recent time when she was going through preparation for a health care assessment for a particular funded service. Her My Care My Way contact said ***'I don't want to dash your hopes,"…. "but it is, it's very difficult to get this funding so be prepared for that."***

Patricia, an unpaid carer interviewed, stated:

***'I found that helpful and (The My Care My Way contact) said, "We're here for you as well" and she did, she was really good.***

### vi. Post Discharge Extra Care Model

For this research, we interviewed people living with dementia who received care at home with an unpaid carer, either their wives or their children. However, we also interviewed people living with dementia residing in extra care facilities.[9]

Extra care facilities provide contained on-site care and fulfil support needs day and night. Out of the participants, three people living with dementia lived in an extra care facility. In this particular study, these interviewees all expressed feelings of gratitude to staff, a sense of trust, a clear single-point of contact, and feeling looked after.

It is notable that in general, they didn't report having the same feelings around the hospital discharge process as other participants. This is most likely due to the extra care facility staff co-ordinating and managing the process and therefore absorbing any issues that arise. They are also the main point of contact for hospital staff and GPs throughout and after the transition. Participants benefited from these long-term and established lines of communication between extra care and other services with quicker and more efficient response times.

***…They said to me the other day they will come to this flat, they're giving us all the treatment, all the medication in time, because they know…they can understand all what they are doing. And after that I found myself feeling better in time'*** – Mahmoud, living with dementia in extra care

***I think it was some sort of ambulance that I was driven in, and I was taken home, and it didn't take very long. And the staff here knew I was coming home, and they seem pleased to see me, and I was pleased to see them, and to get my phone back on.'*** – Hannah, living with dementia in extra care

***It's good. I'm used to this place and wherever I went the staff and the treatment as well so it's good to be in this place.'*** – Bai, living with dementia in extra care

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[9] - For more detail, see Appendix 1: Methodology

# 06 Role of the Researcher

## The importance of being heard

For some participants, the benefits of being actively listened to and heard throughout the course of this research was something that was given as positive feedback to our researcher.

Other notable comments included being treated with patience and kindness. This further highlights not only the importance of their voices being heard but also how this unfortunately conveys a stark contrast to some of their recent experiences.

***'I just wanted to say how useful it was to talk with you this morning & being 'heard', but I also realised when we had finished talking that I wasn't fighting or asking for something, which has been the case for so long now. I feel this is another not recognised, under estimated role that a carer is in frequently.*** – Patricia, unpaid carer

## Signposting

Over the course of the research project, our researcher acknowledged the value of signposting some of the participants to other services. Their feedback shone a light on the fragmented nature of support services. Some participants noted that they knew there were services, but there were so many different organisations and there wasn't a clear road map. The most common services that were hoped for were the first three bullet points on the right: (Two participants each noted these respectfully). Support requested for during the course of the research included:

- **Mental health support for unpaid carers**
- **Transportation to different activities and groups they would like to attend**
- **Increased support at home and respite care**
- Access to incontinence pads
- Befriending
- Escorting
- Digital support due to reduced mobility
- Further activities including gardening, singing and talking therapies for people living with dementia

# 07 Recommendations

**Recommendations in this report are based on the recent conversations our researcher has had with people living with dementia and their unpaid carers in Kensington and Chelsea. Some recommendations are reassertions of good hospital discharge and medical practices as outlined in the National Institute for Health and Care Excellence (NICE) and the UK Government's Hospital Discharge and Community Support Guidance. These are referenced below.**

## 1.Good Practice

### 1.1 Ensure that good hospital discharge practice is executed effectively.

The qualitative evidence contained in this report shows that good practice is not being adequately or reliably followed and so the chief recommendation is that there needs to be consistent execution of good practice across the board.

## 2.Training

### 2.1 A baseline of high quality dementia training for all health care and community care personnel working with people living with dementia and their unpaid carers.[10]

The findings of this report highlight the need for better quality and more specialised dementia training. Although there is currently some training for relevant professionals, this report shows that more needs to be done to ensure learnings are engaged with and consistently followed.

Recognising the importance of improving communication, active listening and emotional intelligence with a dementia-focus would be beneficial. Unfortunately, there remains a cultural stigma surrounding dementia which unless investigated and unpicked, will remain.

This point feeds into a larger cultural picture and it is important that Kensington and Chelsea lead the way on this. There are some great, initial tips here.

## 3.Hospital Environment

### 3.1 Ensure there are dementia-friendly hospital wards.

The lack of familiarity[11] and upheaval of a hospital stay for people living with dementia can cause considerable health setbacks. The hospital experience should not increase isolation or exacerbate dementia symptoms. There must be bright, stimulating wards with windows that allow in daylight. Opportunities for socialisation must be incorporated into the hospital stay and prioritised by staff. The consideration of other helpful aids such as digital devices and/or radios can be vital in maintaining cognitive function.

> ***[They]...put a radio in her room so that she had music in there. She shared the ward with two others but they were all happy with that as well. So it just felt that they were really trying as much as they could to engage with mum to help her to take the meds and everything that she needed.*** - Danielle, unpaid carer

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[10] -National Institute for Health and Care Excellence (NICE). (2018). Recommendations: Staff training and education. In Dementia: Assessment, management and support for people living with dementia and their carers (NG97). Retrieved from Recommendations | Dementia: assessment, management and support for people living with dementia and their carers | Guidance | NICE

[11] - See Appendix 3: Key Dementia Facts

### 3.2 Address emotional/practical support needs during preparation for discharge.

As part of preparation for discharge, it is essential that assistance for people living with dementia and their unpaid carers is provided. This assistance could be emotional/practical support in terms of navigation or ensuring basic needs are met for example, offering food or water.

### 3.3 Ensure patients are discharged safely when they are clinically ready, with timely and appropriate recovery support if needed.[12]

## 4. Communication

### 4.1 Ensuring clear explanation of medical notes, in person & face to face, to both people living with dementia and their unpaid carers.[13]

### 4.2 Ensuring all resources are accessible, user-friendly, and easy to read.[14]

> ***[They] must be aware that the patient has an interest in his own well-being and… should be kept up to date in layman's terms on his condition and how he is progressing. Being isolated in the ward is disturbing and worrisome for the patient.***
>
> – Michael, living with dementia

### 4.3 Ensure early signposting interventions within the hospital environment.[15]

People living with dementia and their unpaid carers should be identified whilst in hospital and offered accessible community mapping information demonstrating what support is available in the borough via appropriate materials.

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[12] - Hospital discharge and community support guidance - GOV.UK (www.gov.uk)

[13] - National Institute for Health and Care Excellence. (2018). NG97: Dementia: Assessment, management and support for people living with dementia and their carers. Royal College of General Practitioners. Health literacy: report from an RCGP led health literacy workshop. June 2014. www.rcgp.org.uk/news/2014/june/~/media/Files/Policy/RCGP-Health-Literacy-2014.ashx.

[14] - National Institute for Health and Care Excellence (NICE). (2018). Recommendations: Dementia: assessment, management and support for people living with dementia and their carers. Retrieved from Hospital discharge and community support guidance - GOV.UK (www.gov.uk)

[15] - ibid

### 4.4 Ensure people living with dementia and their unpaid carers have direct contact numbers for relevant services.

It is essential that people living with dementia and their unpaid carers have direct contact numbers for the multidisciplinary organisations that coordinate for their care. This includes social workers, but also equipment services. There must be clear delivery times and open lines of communication so that individuals can be updated and informed.

## 5. Coordination

### 5.1 Urgent prioritisation of a more joined-up approach

Cementing a joined-up approach where multidisciplinary organisations engage in consistent communication and effective transitions is crucial.

### 5.2 Establish clear single point of access & ownership

Throughout this report, the need for a long-term single point of contact co-ordinating care and liaising with multidisciplinary organisations is evident.[17]

Focus must lie in streamlining & formalising processes so that there is a clear and consistent single point of contact at each step of the discharge process and its transitions. This must also include more frequent check ins.

For the majority of participants in this study, the most recent hospitalisation was just one of many over a number of years; so more work needs to be done to cement long-term support with a clear structure of which service takes ownership and when with increased response times.

### 5.3 Streamline assessment processes

Streamlining assessments, re-assessments and referrals would ensure that the process is as efficient as possible whilst also being able to compile essential patient information. This would also help to alleviate constant repetition and administrative fatigue.[18]

***I think streamlining assessments would be really, really good & essential because it seems that we spend an awful lot of time repeating ourselves, we really do at every level, whether mum's in hospital, whether I'm talking to someone in social services or whether I'm talking to somebody at the surgery, again because they've not read the notes or it's like well now you do need to be reassessed.*** – Patricia, unpaid carer

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[16] - NICE. (2021). Quality statement 3: Coordinated discharge. In Transition between inpatient hospital settings and community or care home settings for adults with social care needs. National Institute for Health and Care Excellence. Retrieved from https://www.nice.org.uk/guidance/qs136/chapter/Quality-statement-3-Coordinated-discharge

[17] - ibid

[18] - National Institute for Health and Care Excellence (NICE). (2015). Recommendations | Transition between inpatient hospital settings and community or care home settings for adults with social care needs. NICE Guideline [NG27]. Retrieved from https://www.nice.org.uk/guidance/ng27/chapter/Recommendations

## 6. Staying out of Hospital

### 6.1 Increase mental health support and training for unpaid carers.[19]

It is vital that targeted mental health support is accessible for unpaid carers. Not only should their emotional well-being be prioritised, but further training should be available to them on their loved one's condition and techniques/tips to ensure they are able to not only look after themselves but also the person in their care.

> ***I think just having the opportunity to talk through the situation would've been helpful…It would be good to just know that what you feel is normal. You know? That, you know, it's gone from high anxiety, to sleepless nights, to actually I can calm down, that sense of fight or flight is gone, and you can kind of just relax a bit, just to talk that through, and just techniques for doing that, and techniques for having a loved one return home. Even a leaflet, or something, just some hints and tips about readjusting to life at home.***
>
> - Danielle, unpaid carer

### 6.2 Increase capacity of community transport.

Expansions of funded and/or subsidised transportation initiatives to get both unpaid carers and people living with dementia safely to certain activities and groups that are borough-wide. This includes dementia-trained staff to assist the transportation.

### 6.3 Increase capacity for one-to-one support for people living with dementia, especially those with more advanced forms.

For many people living with dementia, it may not be appropriate to attend community groups. This can be either due to the type of dementia or a more advanced stage of dementia. It is evident that frequent, specialised one-to-one support for this group makes a huge difference[20] and Kensington and Chelsea is one of the few boroughs in London that provides this service. However, the capacity and resource allocated to one-to-one support does not currently mirror the increasing demand and need for these services. It is vital that there are increased numbers of dementia-specialised workers on the ground.

In addition, the provision of this service must also include working with people living with later stage dementia who currently fall into the gaps of provision in this borough. It is important that this gap is addressed and that they can receive regular home support, for longer periods of time, to foster consistency, familiarity and general well-being.

### 6.4 Prioritise long-term funding of community initiatives

Consistent and long-standing funding is needed to ensure effective community support initiatives with resources and capacity. Fragmentation stemming from pockets of short-term funding fosters instability and unreliable community support options.

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[19] - NICE. (2020). Supporting carers. NICEimpact dementia. Retrieved from https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-use-of-nice-guidance/impact-of-our-guidance/niceimpact-dementia/ch5-supporting-carers

[20] - Alzheimer's Society. (2022). Left to Cope Alone After Diagnosis. Retrieved from https://www.alzheimers.org.uk/sites/default/files/2022-04/left-to-cope-alone-after-diagnosis-report.pdf

### 6.5 Increase dementia-specialised medical personnel in primary care.

Increasing numbers of dementia-specialised professionals in primary care settings would help to take pressures off of secondary care hospitalisations and increase efficient and effective care interventions. In this way, a focus on consistent primary care nurses to provide holistic, person-centred and good quality care would be beneficial.

**The projection for all persons aged 65 and over in Kensington and Chelsea for the next 20 years is higher than all other London authorities.[21] It is estimated that over 3,100 people across Kensington, Chelsea and Westminster are living with dementia and by 2030 this figure is expected to rise to over 5,500.[22] It is vital, in particular for this borough, that the challenges that people living with dementia and their unpaid carers face throughout the hospital discharge process are creatively and realistically addressed to bring about real change and contribute to Kensington and Chelsea becoming more dementia-friendly.**

> ***If this helps someone else or it helps to actually change the system in some way then that will be a real achievement.***
> - Patricia, unpaid carer

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21 - Age UK, National Age UK Area Profile (Full) (2022). Population and Prevalence report for England [Report]. Retrieved from LG Inform website: https://lginform.local.gov.uk/

22 - Royal Borough of Kensington and Chelsea. (May 30, 2024). Shining a Blue Light on Dementia Across Kensington, Chelsea and Westminster. Retrieved from https://www.rbkc.gov.uk/shining-blue-light-dementia-across-kensington-chelsea-and-westminster

# 08 Acknowledgements

21

We are very grateful for the funding from Kensington & Chelsea Social Council on behalf of Central London Community Healthcare who made this research possible.

We would like to extend our gratitude to all the people living with dementia and unpaid carers who have been involved in this project. Thank you for your time, insight and determination to share your experiences to make a positive impact.

All images used in this report are via Centre For Aging Better's age-positive image library.

# 09 Appendices

## Appendix 1: Methodology

This research report is a non-academic piece of qualitative research.
Our researcher spoke to a sample of 6 persons living with dementia in the borough of Kensington and Chelsea and 4 unpaid carers. This sample had recently all had experiences of the hospital discharge within a 4 month time frame from the beginning of this project.

We recruited participants through our existing dementia services at Age UK Kensington and Chelsea, independent outreach to extra care facilities including Octavia, community organisations and online advertising through the Carers Network.

The interviewees comprised of 4 men and 6 women. All unpaid carers interviewed were women, either spouses or family members of people living with dementia. Out of the people living with dementia interviewed, 3 were living in extra care facilities, 1 lived alone in a housing association, and 2 lived with their spouse.

70% of those interviewed spoke English as a first language.

### Demographic Chart Comparison

Demographics for this research sample had some similarities with the national statistics for over 65s in Kensington and Chelsea.[23] However, comparatively non-white participants with differing ethnic backgrounds were represented more in this sample and white participants made up 60% of the total as opposed to 75.5% across the borough. In this way, a more diverse range of backgrounds, views and voices were included.

Please see comparative pie charts on page 30.

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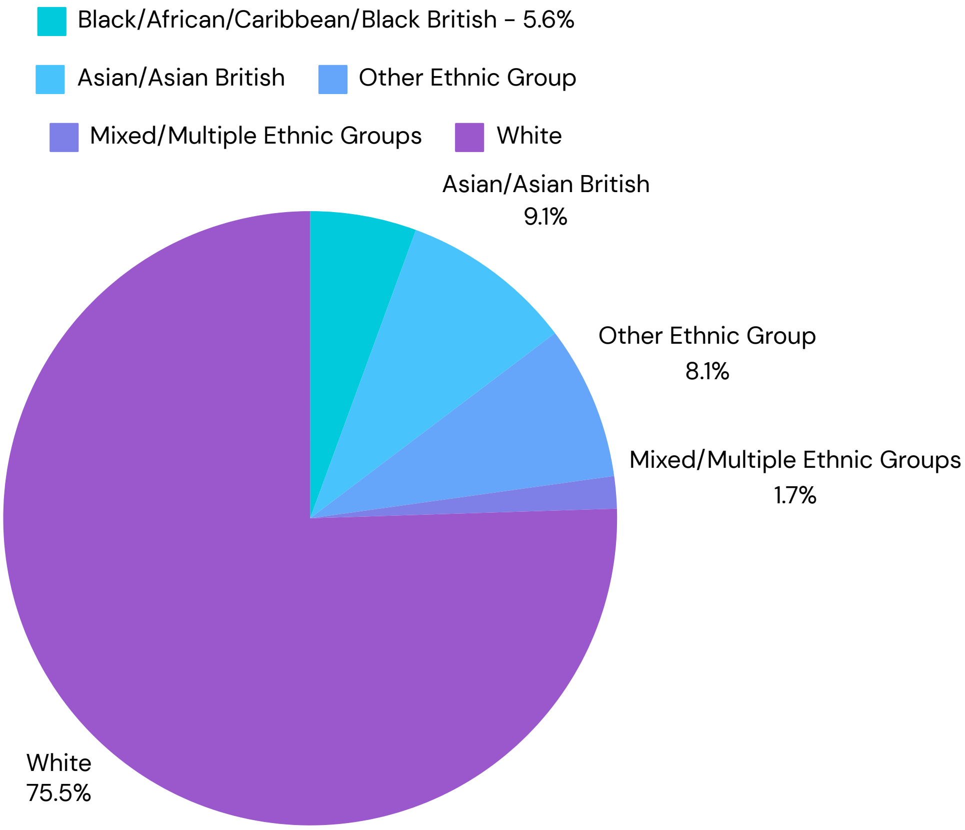
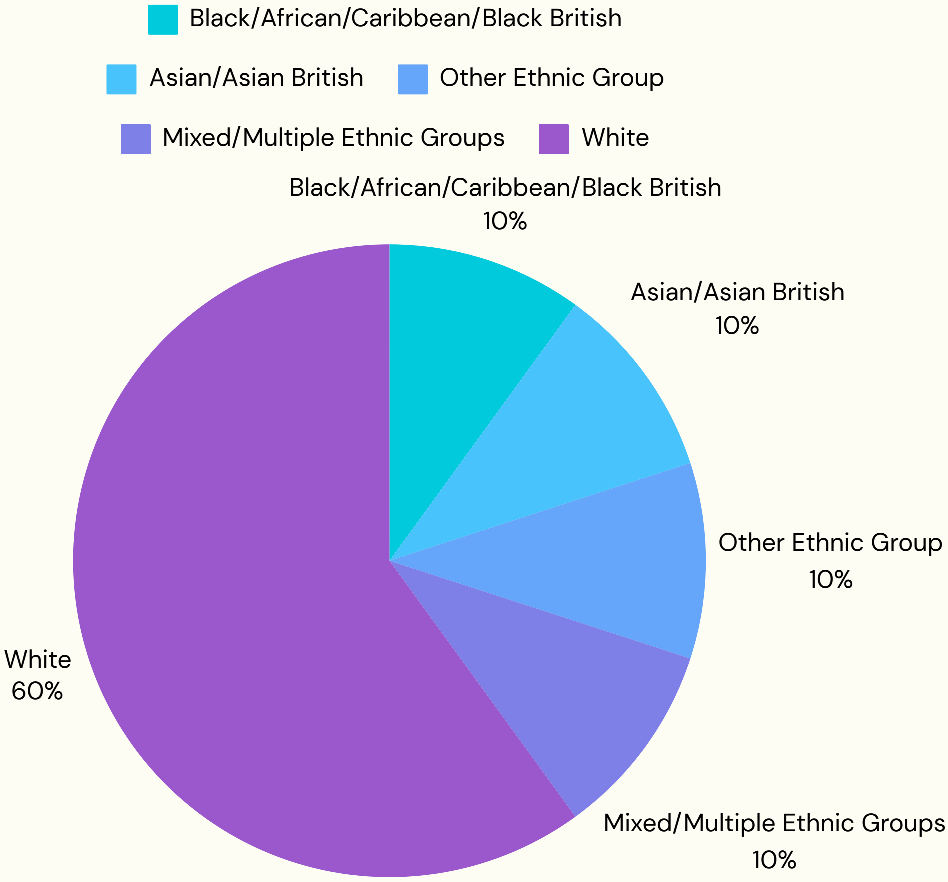
23 - Age UK, National Age UK Area Profile (Full) (2022). Population and Prevalence report for England [Report]. Retrieved from LG Inform website: https://lginform.local.gov.uk/

# Proportion of the population aged 65 and over by ethnic group for Kensington and Chelsea:



# Proportion of hospital discharge study participants by ethnic group:

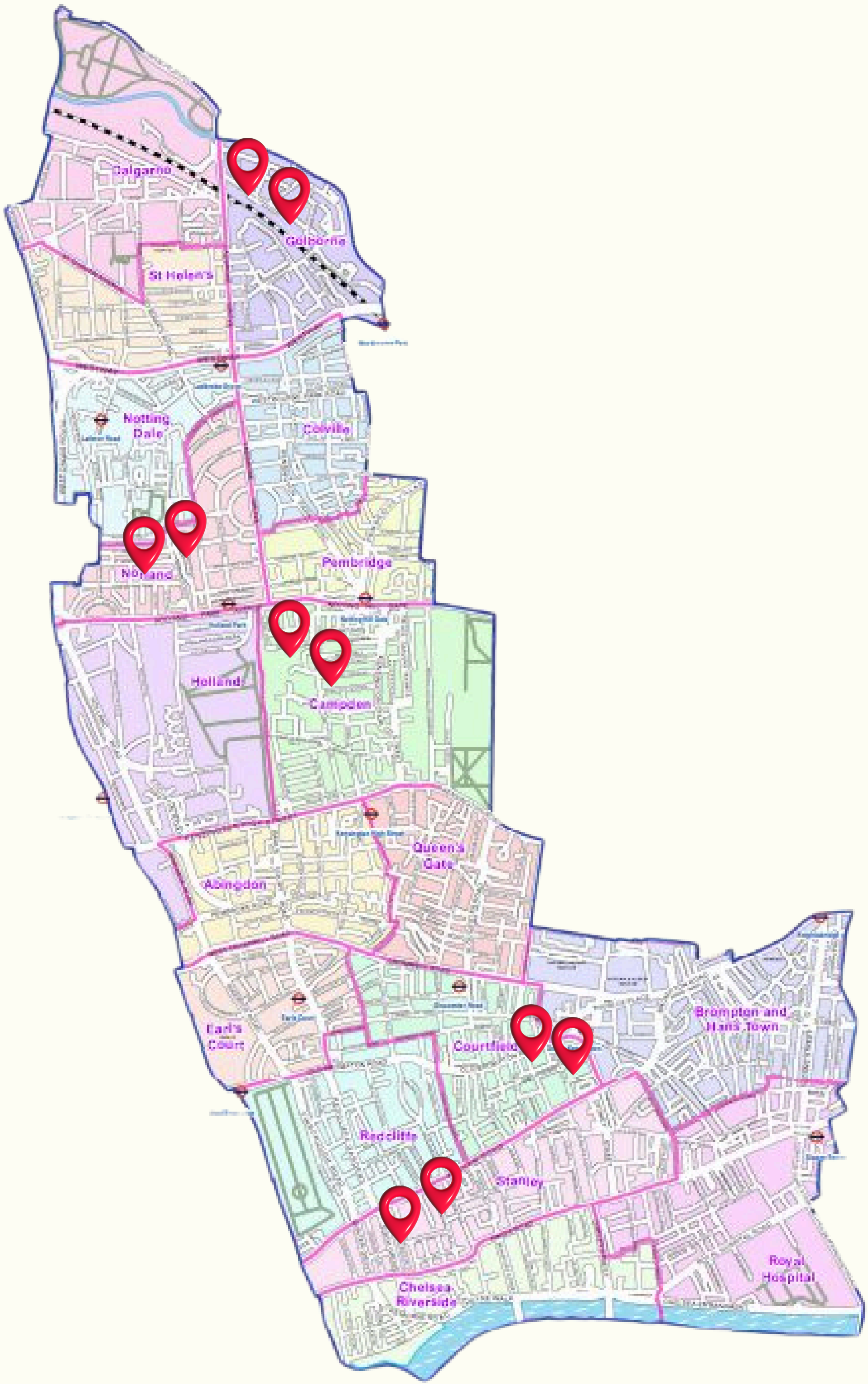


# 09 Appendices

## Appendix 1: Methodology

### Ward Representation

The location pins on the map of the borough of Kensington and Chelsea below show the wards represented by participants in this study. Those are, Norland ward (20%), Golborne ward (20%), Stanley ward (20%) Courtfield ward (20%) and Campden ward (20%). For a small sample, there is solid representation of voices from both the north and south of the borough.



# 09 Appendices

## Appendix 1: Methodology

### The Interviews

Interviews with participants were conducted flexibly where the interviewee felt most comfortable. This included at our office in Ladbroke grove, within participants' homes and also over the phone. The length and content of interviews was participant-led, although a Topic Guide could be requested for guidance by the interviewee.

Participants could also request a Declaration of Ethical Principles document created by our Researcher to ensure the ethical treatment of vulnerable participants throughout.

The majority of participants gave 3 interviews, the first being at the closest time period to the recent hospital discharge experience and the last roughly 3 months after the first. However, one participant was unable to do their final interview. 29 Interviews were conducted in total from January 2024 - May 2024.

Interviews were recorded using a ZoomHn4 audio recorder and the majority of these were professionally transcribed by TP Transcription. All interviews were scheduled flexibly and based around the needs and comfortability of the participant.

Participants were recruited flexibly, on a rolling programme and were given a Study Brief and a detailed Participant Information Pack created by our Researcher. The latter contained layered areas of consent to participate, including consent to have their voices heard in the Audio Story. Participants could choose whether they wanted to be named or not in the research. For participants who did not wish to be named, pseudonyms were used. Participant well-being was prioritised and assessed either through a ONS4 well-being assessment at first and final interview or verbally throughout where this was more appropriate.

### Challenges

The unique criteria of this research project posed a challenge and there were some deviations from the original methodology. Not only did certain criteria need to be met:

-A person living with dementia or an unpaid carer of someone living with dementia
-Must have had a recent hospital admission/discharge

But the majority of the participants are among the most hard to reach and vulnerable groups in this borough. Many were also going through a very emotionally difficult and turbulent time. This meant extra work was focused on outreach. However, it also meant that a strict, formulaic approach to interviews being conducted at specific moments of the discharge timeline was not realistic or compassionate. In this way, the importance of a completely flexible, person-centred approach was re-enforced.

## Appendix 1: Methodology

### Comorbidities

Nearly 9 in 10 people living with dementia have at-least one other health condition.[24] This statistic was echoed and magnified in this study as all relevant participants had at least one, and some multiple, comorbidities alongside their dementia diagnosis. The participants living with dementia in this research were admitted to hospital for various reasons, with Urinary Tract Infections being the most common. Disclosed comorbidities included:

- Urinary Tract Infections and associated delirium
- Delirium
- Hallucinations
- Hypertension
- Broken or fractured bones from falls
- Breathing and chest problems
- Eye infections
- Infarctions
- Parkinson’s disease
- Diabetes
- Vision and hearing loss
- Epilepsy
- Severe mental health issues such as depression and schizophrenia
- Severe eczema, psoriasis
- Reynaud’s Disease

In addition to the list above, participants living with dementia who were part of this study also had varying types of dementia including **Alzheimer’s disease, Vascular Dementia and Dementia with Lewy-bodies.**

The complexity of these comorbidities alongside existing and varying dementia diagnoses elevated the nuanced, individual physiological difficulties and highlights the base-level adversity faced for people living with dementia and their unpaid carers.

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24 - Browne J, Edwards DA, Rhodes KM, Brimicombe DJ, Payne RA. Association of comorbidity and health service usage among patients with dementia in the UK: a population-based study. BMJ Open. 2017 Mar 9;7(3):e012546. doi: 10.1136/bmjopen-2016-012546. PMID: 28279992; PMCID: PMC5353300.

## Appendix 2: Community Mapping

Throughout the course of this project, it became apparent just how important effective community mapping is and the importance of raising awareness of services in this borough. **Services highlighted are free unless cost or privately-funded options are specifically stated.**

The community map below is up to date as of **May 2024** however, it is not exhaustive. There are new initiatives being piloted this year, including the Dementia Roadmap (listed at the end of the community map) which can help people living with dementia, their carers and professionals working in the borough to find an array of services, together, in one online space. It is currently in development stage.

NHS
Central and
North West London
NHS Foundation Trust

### Kensington & Chelsea and Westminster Memory Service

**What they do:** The Memory service provides assessment and diagnosis of dementia and provide ongoing support and information to people with memory problems and their carers.

Memory services are specialist services for people of any age who may be experiencing memory difficulties, which includes early onset dementia.

All teams have access to medical staff, specialist dementia nurses, occupational therapists, and psychologists. Admiral Nurses are also incorporated into this team who specialise in supporting carers.

The Memory Service also collaborates with community organisations such as Resonate Arts for Cognitive Stimulation Therapy (CST) programme at the V & A, Dementia UK and Age UK Kensington and Chelsea.

**What you can expect:** People can be referred to memory services by their GP or directly via another specialist practitioner such as a neurologist or medical staff in another hospital. In the latter case, the Memory Service will inform the GP of the referral.

**Are there waiting times?**
Yes as they are a small team. However, they do prioritise referrals based on risk.

**020 3317 3666**
**wmsreferrals.cnwl@nhs.net**

**42 Westbourne Park Road**
**Kensington & Chelsea**
**London**
**W2 5PH**

**www.cnwl.nhs.uk/services/mental-health-services/adult-and-older-adult/kensington-and-chelsea-and-westminster-memory-service**

# 09 Appendices

## Appendix 2: Community Mapping

### Age UK Kensington and Chelsea

**We are an independent, local charity working at the heart of the community to make sure that older people's voices are heard, their needs are met and their independence is supported. We work in partnership with other organisations on various projects and provide a wide range of services including:**

- Dementia & Memory Loss Services
- Care at Home
- Health & Support
- Help in your GP surgery - My Care My Way
- Digital Inclusion Services
- Information & Advice
- Befriending (one to one)
- Escorting
- Exercise at Home/Walking Support
- Group Shopping Trips
- Basic Foot Care
- Simple DIY Service

**Information for most relevant services for people living with dementia and unpaid carers are listed below.**

### One-to-one Dementia Support

### Dementia Support Workers

**What they do:** Our Dementia Support Workers make weekly visits to support someone living with dementia to pursue their interests, maintain independence and retain social contacts.

**What you can expect:** Friendly and personalised support with no cost.

**How do I get referred?**
You can refer someone living with dementia to Age UK Kensington and Chelsea. Referrals can also come via GPs, Kensington & Chelsea and Westminster Memory Service and various health care professionals. Our Support Workers and Dementia Advisor can inform you of referral criteria & eligibility.

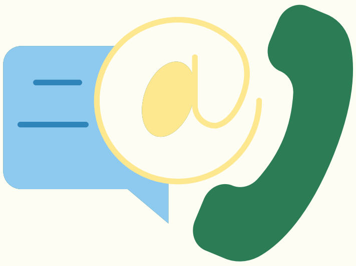
Our dementia team will go through an assessment with you. We are a small team providing borough-wide support - please allow time for referral to be processed.

Membership for Age UK Kensington and Chelsea is free

### Dementia Advisor

**What they do:** If someone has been recently diagnosed with dementia or has ongoing issues with memory loss, our Dementia Advisor can provide support to the person with memory loss, their carers and/or family to navigate local services.

**What you can expect:** Informative, informal conversations including signposting and next steps.



**For more information on one-to-one support, contact our Dementia team: 020 3181 0002**

**DementiaDistribution@aukc.org.uk**

# 09 Appendices

## Appendix 2: Community Mapping

### Age UK Kensington and Chelsea

### Group Dementia Support

**Memory Cafés**

Our Memory Cafés are monthly gatherings for people with early to moderate stages of dementia or memory loss. Memory Cafés are also open to friends and family of users.

**What you can expect:** Memory Cafés are a safe place to connect, socialise, share resources, be creative and support one another.

They are held in the North (first Wednesday of the month - Portobello) and South (last Wednesday of the month - World's End) of the borough.

If you want more information please contact our Dementia Advisor on **020 8 969 9105 (ext. 5) or 07508341127.** Alternatively, you can email at: **mandrews@aukc.org.uk**

**Is there a waiting list?**
No, there are spaces. Contact the above numbers to ask about attendance.

### Care At Home - Respite Care

Our At Home services provide respite care, enabling caregivers to take a planned break for a few hours, secure in the knowledge that their loved one has been provided with continuity of care.

Our At Home Assistants are able to offer companionship and any practical support that you would usually provide, keeping disruption of routine to a minimum.

We provide both funded respite as well as a self-funded service. Please note we do not provide Personal Care.

**Funded Respite**
You may be eligible for funded respite care for up to 3 hours a week. Call the number below for more information about eligibility criteria.

**Self-funded Respite**
If you do not qualify for funded respite, if funded respite was not available, or if you would like more hours, we offer a paid for service at the cost of £26 per hour. Please contact us to arrange this. For more information get in touch below:

**020 89699105**
**athome@aukc.org.uk**

## Appendix 2: Community Mapping

### Age UK Kensington and Chelsea

### Help in your GP surgery – My Care My Way

**What they do:** My Care My Way (MCMW) is an integrated health service for people aged 65+ available through your GP surgery. It is provided by local NHS community services and Age UK Kensington & Chelsea.

As this report shows, managing your health and care can be difficult, especially when you are dealing with many different professionals and multiple services. MCMW aims to bridge these gaps in the system.

**What you can expect:** MCMW will pair you with a worker who will help you negotiate a system that can be very confusing. You will be allocated a Health and Social Prescribing Co-ordinator and Case Manager who are based in your GP surgery. They will work in partnership with you and the GP. You will be given the opportunity to discuss your overall health and circumstances with your GP in an extended 6-monthly or annual review.

**How do I get referred?**
To receive a referral, contact your GP and ask to talk to them about the My Care My Way Service

**You can also contact the MCMW team to ask further questions about the service at: clcht.ictadminteam@nhs.net**

**Age UK Kensington & Chelsea**

1 Thorpe Close
London
W10 5XL

Phone: 020 8969 9105

Email: info@aukc.org.uk

## Appendix 2: Community Mapping

### Admiral Nurses

**What they do:** Admiral nurses are specialised mental health nurses supporting carers of people living with dementia. They provide information, practical advice and emotional support if you are caring for a relative or friend who has dementia. They can help with obtaining professional assessments, support services, welfare benefits and relief care.

**What you can expect:** Admiral Nurses accept referrals from healthcare professionals GPs, CMHT, My Care My Way, Memory service and other heath clinic/departments. They will check that you meet the criteria for the service and a referral form will be completed by your referrer.

**Is there a waiting list?** Yes. As the Admiral Nurses are a small team, expect some waiting time and time for the referral to be processed.

**wmsreferrals.cnwl@nhs.net**

**Kensington Chelsea and Westminster Admiral Nurses: 020 3317 3667**

**Admiral Nurse Dementia Helpline: 0800 888 6678**

### Community Independence Service (CIS)

**What they do:** The Community Independence Service (CIS) is an intermediate care service providing advanced short- term nursing care, occupational therapy, physiotherapy and social care to people with immediate health or functional needs, who would otherwise require an admission to hospital.

The service aims to offer safe care at home which enables people to avoid unplanned hospital admissions.

**What you can expect:** CIS is available 7 days a week from 8am to 10pm for adults over the age of 18 whom reside in (includes nursing and care homes) and are registered with a GP in Kensington & Chelsea, Hammersmith & Fulham or Westminster.

**How do I get referred?**
Referrals are only via GPs, clinicians, health or care professionals or Social Services. Relevant professionals can inform you about whether you fit the referral criteria for this service.

**cnwl.cis3borough@nhs.net**

**www.cnwl.nhs.uk/services/community-services/community-independence-service**

## Appendix 2: Community Mapping

### Chamberlain House Dementia Resource Centre

**What they do:** Chamberlain House are a Dementia Friendly Day Service specialising in complex needs. They provide person centred care for Older Adults (Over 65s). People with all abilities are welcome.

**What you can expect:** They provide a subsidised three course lunch with snacks and beverages served all day.

They host various activities such as Arts & Crafts, Poetry, Music & Movement, Chair Based Exercises, Sing-Along, Quizzes, Cook &Taste & ing.

**How do I get referred?** Any person can make a referral via a Social Worker / Mental Health Team Psychiatrist / Occupational Therapist or GP. Ask these relevant professionals about specific referral criteria.

**chamberlainhouse@rbkc.gov.uk**

**Reception: 020 3927 7995**

**Chamberlain House**
**St Charles's Centre for Health and Wellbeing**
**W10 6DZ**

### The Herbert Protocol

**What is it?:** When a person goes missing, it is very distressing for family and friends and can be even more worrying when the missing person is living with dementia.

The Herbert Protocol is a simple risk reduction tool to help the police in their search for people living with dementia who go missing. It encourages carers or family members of adults living with dementia to collate information on those who are vulnerable on to the Herbert Protocol form, which can be given to the police if they go missing. (Link to form is below) The police only need the form at the point the person is reported missing.

The initiative is named after George Herbert, a war veteran of the Normandy landings, who lived with dementia. He died whilst 'missing', trying to find his childhood home.

If you believe a person has gone missing and concerned for their safety, call the police on 999 and tell the police operator that you have a Herbert Protocol.

The Herbert Protocol Form

Age UK Information on The Herbert Protocol
Age UK Herbert Protocol Guidance

## Appendix 2: Community Mapping

OCTAVIA

### Kensington Day Centre at The Reed

**What they do:** The Kensington Day Centre (KDC) run by Octavia at The Reed offers an inclusive and accessible space at The Reed for older people to meet, eat, and get active or be creative and improve their wellbeing, with the support of a specialised day-care team. They offer Drop Ins as well as a Day Centre service.

**What you can expect:** There are lots of activities held at the Reed that visitors to the day centre can take part in such as arts and crafts and chair exercise. They also collaborate with other organisations such as Age UK Kensington and Chelsea to host activities such as the Memory Café.

They also offer a 3 course lunch for £6.50 which includes refreshments throughout the day.

If you are referred via Social Services, they can help with arranging accessible transport to pick you up at a convenient time and drop you back home again safely.

KDC can take referrals from Social Services, drop ins and privately-funded visitors.

Privately-funded clients must provide own transport and prices are slightly higher for more complex needs. To find out more give them a call (details below.)

**Are there spaces?** Yes, they do currently have spaces as of May 2024.

**020 8354 5594**
**020 8962 3570**

**info@octavia.org.uk**

**www.octaviasupport.org.uk/contact/our_scheme_locations/178_the_reed**

**28 Convent Gardens**
**W11 1NJ**

## Appendix 2: Community Mapping

**The Pepper Pot Centre**

**What they do:** The Pepper Pot Centre provides a day centre and drop in service for over 60s, from the African, Caribbean & other BME communities to enable them to live more independently.

The Pepper Pot Centre seeks to combat isolation, depression, loneliness and discrimination. They provide a variety of fun and engaging activities to support members, including those with dementia, to increase their physicality and well-being.

**What you can expect:**

Pepper Pot Centre considers private referrals from individuals, family & friends to referrals from Social Services, GPs & Healthcare personnel as part of a tailored care package.

They can arrange minivan pick ups for a small fee through social care referrals.

Members can enjoy a healthy balanced Caribbean meal and recreational services.

Day Care members can benefit from on-site carers catering for specialised needs, including dementia. Active elderly members are able to use their drop in services.

Pepper Pot Centre plan to have more collaborative dementia-focused projects in the near future.

**Are there spaces?** Yes, but subject to referral being accepted and processed.

**020 8968 6940**

**reception@pepperpotcentre.org.uk**

**www.pepperpotcentre.org.uk**

**1A Thorpe Close**
**Ladbroke Grove**
**W10 5XL**

## Appendix 2: Community Mapping

### Resonate Arts

**What they do:** Resonate Arts offers a range of inspiring and fun arts groups and creative opportunities for people living with dementia, their carers and family members. This includes singing, both online and in person, art sessions, collaborations with the V & A, an accessible movement group and a Creative Befriending service. They operate in the boroughs of Kensington & Chelsea and Westminster.

**What you can expect:** A friendly welcome call to find out more about what they can offer and so they can find out about your creative interests. You can also expect safe and supportive social groups where people can creatively express themselves and make new friends.

**Are there currently spaces?** Yes, there are currently spaces in many of their groups. You can get in touch below to book:

**0300 030 7212**
**info@resonatearts.org**
**www.resonatearts.org**

**Resonate Arts**
**37 Chapel Street**
**London**
**NW1 5DP**

### Carers Network

**What they do:** Carers Network was established in 1991 to support unpaid carers. They support people caring for partners, family members, friends and neighbours aged over 18 with disabilities and long-term conditions or experiencing frailty due to old age. Carers Network provides one-to-one assessments, an information and advice service, support groups and drop-in sessions. In addition, they have a programme of events, activities and training.

**What you can expect:** Carers Network's services are available free of charge to unpaid carers living in the Royal Borough of Kensington and Chelsea, the City of Westminster and the London Borough of Hammersmith and Fulham. You can self-refer if you are an unpaid carer via their webform below. Professionals can also refer carers via this form. Alternatively, carers can call the number listed below to register.

**Are there spaces?**
Yes, you can join the network if you are an unpaid carer in the relevant boroughs. Allow some time for referral to be processed. Please visit their website below for more details.

**020 8960 3033**
**info@carers-network.org.uk**
Webform:
**www.carers-network.org.uk/help-and-advice/register-for-support**
Website:
**www.carers-network.org.uk**

## Appendix 2: Community Mapping

### Open Age – Time for Me Project

**What they do:** The Time for Me Project makes it possible for unpaid carers over 50 to take some time out to relax, meet other carers and have some fun. They organise regular free or low cost activities and social events as well as short trips around London. These include visits to museums, coffee mornings and spa days.

**What you can expect:** To access this project, you will need to become an Open Age member (this is free) and complete a Time for Me form. This can be done online, in-person at one of their centres or over the phone.

Most of the activities are free, but some may have a low cost or ask for small donations. You can see their upcoming activity schedule on their website.

**Is there a waiting list?**
No, there are spaces. Allow a short amount of time for membership and Time for Me forms to be processed.

**020 4516 9976**
**carerstimeforme@openage.org.uk**
**www.openage.org.uk/carers-time-me**
**www.openage.org.uk**

### Open Age – The Revellers Club

**What's the project?:** Open Age are partnering with the Royal Albert Hall for The Revellers Club, a multi-arts project for people living with dementia and their carers. Each session focuses on a different artform or theme inspired by the Royal Albert Hall's history.

The Revellers Club is dementia-friendly and has been created in consultation with local community organisations supporting people living with dementia and their carers.

**What you can expect:** To access this project, you register through the contact, Ed, below at the Royal Albert Hall. Sessions take place at the Royal Albert Hall's North Circle Baron the first Thursday of each month throughout the year.

**Is there a waiting list?**
No, there are spaces. The capacity for each session is 20, including carers. The sessions are first come first serve but consistent users will be prioritised.

**02079590540**
**Ed Cobbold:**
**engagement@royalalberthall.com**
**www.royalalberthall.com/tickets/events/education/the-revellers-club/**

## Appendix 2: Community Mapping

### The Kensington and Chelsea over 50s Forum

**What they do:** The Kensington and Chelsea over 50s Forum has been active since 1996 and gained The Queen's Award for Voluntary Service (QAVS) in 2017.

They host regular meetings at their three Master Hubs located in W8, W11, and SW7. Their goal is to provide members with essential information on various topics, including health and long-term condition management, legal issues, scam and fraud awareness, and access to local and regional services.

Additionally, they emphasize cultural enrichment, host annual conferences and offer members various initiatives such as:

- A Safeguarding and Health Scrutiny Group
- Campaigns to improve services for older people
- Two Digital Hubs in W10 and SW3
- Weekly Tai Chi sessions in W11
- Weekly chair exercises in W10 and SW10
- Creative projects in collaboration with museums and businesses.
- Social activities

**What you can expect:** Membership is free, and all of their regular activities are free to join at the present time. However, there is a fee for trips and some creative activities.

**Are there spaces?**
Yes, there are spaces and they are welcoming new members. You can get in contact with them below to find out more about joining the forum.

**0203 719 4954**

**kensingtonandchelseaforum@outlook.com**

**www.kensingtonandchelseaforum.org.uk/**

## Appendix 2: Community Mapping

### Westway Community Transport

**What they do:** Westway CT are a community transport organisation that help people in Kensington and Chelsea & Westminster get to where they want to be. They offer a range of accessible community transport solutions for people over 50 who struggle to use mainstream public transport due to age or mobility issues and difficulties.

Services offered include free shopper buses and days out, and a volunteer car service at heavily subsidised rates (For example, a £4.40 contribution covers 7 miles travelled).

Individual members request their transport independently, but Westway CT also works in collaboration with voluntary and community organisations booking transport on behalf of their members needing to attend their classes or events.

**What you can expect:** To use these services, you need to be a Westway CT member, which costs £12 a year. You can call them at to request membership or fill out the online form on their website. They can either email or post a membership form to you to fill out if that is preferred. Payment for this can be taken flexibly over the phone, by bank transfer, by cheque or online.

The information you provide is self-declared and doesn't require a medical referral.

Once you are a member, they can either email or post a detailed welcome pack to you including all the information, timetables of group services and how to book.

**Are there spaces?**
Yes, however, once you are a member it is encouraged to book in advance as spaces are on a first come first serve basis. It is also encouraged to book in advance for the volunteer car service to give Westway CT as much time as possible to find a volunteer driver for your journey.

**0208 9644928**
**info@westwayct.org.uk**

**Westway CT | Community Transport & Training Services**

**240 Acklam Road**
**London, W10 5YG**

## Appendix 2: Community Mapping

### Kensington Leisure Centre & Chelsea Sports Centre – Active for Life

**What they do:** The RBKC Active for Life programme provides free and low cost activities taking place within Kensington and Chelsea. The RBKC Sports Development Team, in partnership with local organisations across the borough, provide activities for all abilities and backgrounds. There are also specialised sessions for seniors.

**What you can expect:** Although there are no dementia-specialised classes, people living with dementia are able to attend with their carers. You can see their upcoming activity schedule on their website and book under the 'Active for Life' section.

**How can I get in touch?**

**Chelsea Sports Centre:**
**020 7352 6985**
**Chelsea.enquiries@gll.org**
**Chelsea Manor Street, SW3 5PL Web:**
**www.better.org.uk/chelsea**

**Kensington Leisure Centre:**
**020 3793 8210**
**Kensington@gll.org**
**Silchester Road, W10 6EX**
**www.better.org.uk/kensington**

### Picturehouse – Fulham Road

**What they do:** Picturehouse cinema on Fulham Road offers dementia friendly film screenings on the last Friday of the month, 11am.

Dementia Friendly Screenings are open to all, but aim to make cinema more accessible to local dementia communities by providing a fun, friendly and inclusive experience for people living with dementia. The lights are left on low, there are no adverts or trailers and the audience is allowed to move around – or sing along to any musical numbers should they wish to.

**What you can expect:** Free tea, coffee and biscuits are served for half an hour before the film to give people the chance to meet and socialise with others, and to familiarise themselves with the cinema space and there is extra signage put up to help you navigate the building. There is also an interval half-way through the film.

Tickets are at the reduced price of £4.30 per person, with a free place for accompanying carers.

**Accessibility phone line: 0207 294 7908**
**Over the phone bookings: 0871 902 5747**
**enquiries@picturehouses.co.uk**

**Picturehouse Dementia Friendly Screenings**

**142 Fulham Road, Kensington SW10 9QR**

## Appendix 2: Community Mapping

### Chelsea Physic Garden

**What they do:** Chelsea Physic Garden runs activities both indoors and outdoors that are nature related. Their Forget-me-nots programme provides socialising and dementia-friendly activities for people living with memory loss, their families, friends and carers.

**What you can expect:** Hot beverages and biscuits will be provided. People living with dementia will need to be accompanied by their carers. However, Chelsea Physic Garden have a team of dementia-friendly volunteers on hand to chat, answer questions and help showcase the garden - potentially providing some respite for carers.

There is no fee and no means testing to attend. After the activities are finished, you are welcome to remain in the garden for as long as you like. There is also a café on site if you would like to pay for refreshments after the session.

**Is there a waiting list?**
No, there are spaces as of May 2024. You can register your interest by phone or email.

**0207 349 6474 or 02073525646**
**learning@chelseaphysicgarden.co.uk**

**chelseaphysicgarden.co.uk/forget-me-nots**
**www.chelseaphysicgarden.co.uk**

### Royal Hospital Chelsea

**What's the project?:** As of **September 2024,** the Royal Hospital Chelsea will be opening a new visitor centre in its historic stable yard complex, thanks to a project generously supported by the National Lottery Heritage Fund. Once open, the space will host a variety of new programmes for people with dementia, their loved ones and carers.

There will be different groups each week on a monthly basis, including singing groups, drop in memory and social cafes, dementia-inclusive tours and arts & heritage activities. These activities will be supported by the City Bridges Foundation.

**What you can expect:** It is advised that people living with dementia are ideally accompanied by a carer or loved one. More information regarding the community projects will be available soon on the Royal Hospital's website.

**Is there a waiting list?**
No, the project begins in September 2024. It will be first come first served. You can register your interest in these activities now by contacting Marina Spiteri, the Royal Hospital's Community Engagement & Outreach Manager by phone or email.

**0207 881 5493**
**marina.spiteri@chelsea-pensioners.org.uk**

**Location: (Opening in September 2024)**
**Soane Stable Yard Works | Royal Hospital Chelsea (chelsea-pensioners.co.uk)**

**Website: Home | Royal Hospital Chelsea (chelsea-pensioners.co.uk)**

## Appendix 2: Community Mapping

### Dementia Road Map – Dementia Pathfinders & Dementia Action Alliance

**About the Dementia Road Map:** It is a web based platform that is currently being developed for Kensington and Chelsea to provide up to date information about the dementia journey alongside local information about services, support groups and care pathways to assist primary care staff and others to more effectively support people with dementia, their families and carers. Local editors will populate the Roadmap with resources and groups that are relevant to their locality.

The Dementia Roadmap has been developed in a partnership between the Royal College of General Practitioners and the Department of Health and is hosted by Dementia Pathfinders.

The Kensington & Chelsea and Westminster Dementia Action Alliance (A coalition of local dementia- focused organisations) has also noted a lack of a reliable directory of local services and has brokered an agreement with Dementia Pathfinders to pilot this service in our area.

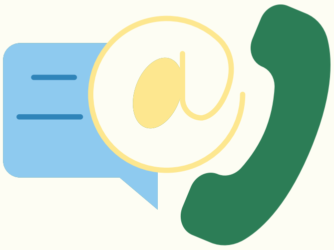
**What you can expect?**

**Users:** Although the Dementia Roadmap is still in its early stages, it will hopefully contribute to better awareness of local services by bringing them together in one online space.

**Services:** It is free to list your service on this platform. Please email the contact below for more information on how to do this and request a form.

**Until further notice any questions and completed forms should be returned to: jude@resonatearts.org**

**www.dementiaroadmap.co.uk**



**Dementia Roadmap**

A directory of dementia services in local regions throughout the UK

Dementia Roadmap

## Appendix 2: Community Mapping

**MORE INFO**

www.peoplefirstinfo.org.uk

www.lottie.org

www.homeinstead.co.uk/kensington-chelsea/

www.verilife.co.uk

www.dementiauk.org

**0800 888 6678** – Admiral Nurse Dementia Helpline

www.alzheimers.org.uk

www.ageuk.org.uk

www.rbkc.gov.uk

**020 7361 3013** – Social Services Line

## Appendix 3: Key Dementia Facts

It is important to bring attention to some key facts about dementia which are relevant when we consider and evaluate findings from the Realities of Hospital Discharge report.

### Individuality

Each person's experience of living with dementia is unique and individual. People living with the same type of dementia on paper may exhibit vastly different symptoms. In addition, different types of dementia also tend to affect people differently as well.[25] In this way, it is vital to take into account the individual as a whole to understand how their dementia manifests and interacts with other health conditions they may have. Recognising this individuality can have a beneficial influence to approach strategies, communication and treatment of the individual.

### Familiarity

Familiarity and consistency for people living with dementia is crucial. This familiarity can mean recognising a particular person, a feeling that person elicits within them or a place, as something they have experienced before. Experiencing non-familiarity may lead to insecurity and disorientation, fear about personal safety, social exclusion and a decrease in participation outside home.[26]

### Social Interaction

Social interaction is healthy and can slow symptoms of dementia including[24] decreasing cognitive function. Ensuring a good social environment around people living with dementia increases well-being, which in turn can result in better patient outcomes.[27] This doesn't necessarily entail large social groups, especially for people with more advanced or differing types of dementia. Consistent, quality one-to-one interaction can be more beneficial and effective depending on the individual.

### Communication

Good communication can help people to live well with dementia.[28] This includes being listened to, being understood and also being able to understand others who are communicating with them. Dementia-informed communication styles can help aid this process and minimise detrimental interactions. Tips on communication can be found here.

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25 - Alzheimer's Society. (n.d.). What is dementia? Retrieved from https://www.alzheimers.org.uk/about-dementia/types-dementia/what-is-dementia

26 - Margot-Cattin, I., Kühne, N., Öhman, A., Brorsson, A., & Nygard, L. (2021). Familiarity and participation outside home for persons living with dementia. Dementia (London, England), 20(7), 2526–2541. https://doi.org/10.1177/14713012211002030

27 - Dementia Care Central. (n.d.). Socialization and activities for people with dementia. Retrieved from https://www.dementiacarecentral.com/caregiverinfo/handsoncare/socialization/

28- Alzheimer's Society. (n.d.). Communicating and dementia. Retrieved from https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/communicating-and-dementia

# The Realities of Hospital Discharge

*Conversations with people living with dementia and unpaid carers on their recent experiences of the hospital discharge process in Kensington and Chelsea*

**Age UK Kensington & Chelsea**

1 Thorpe Close, London, W10 5XL

020 8969 9105

info@aukc.org.uk

www.ageuk.org.uk/kensingtonandchelsea

Researched and written by: Harriet Wills

**Kensington & Chelsea Social Council**

(Museum of Brands - Car Park Entrance)
111-117 Lancaster Road
London
W11 1QT

020 7243 9800

info@kcsc.org.uk

www.kcsc.org.uk

Charity number: 1082658

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