

# City and Hackney Guide to Dementia and Family Relationships

A guide to help you understand and  
manage dementia in the family.



## Introduction

---

We have written this guide to help people who have a family member or friend who has dementia. This can be a difficult time for everyone and this guide offers suggestions to help you through this journey. For the purposes of this guide, we will refer to the person with the diagnosis as the 'Person with Dementia', PwD for short. This may be a new term for people reading this guide but it is not always family members who are caring for someone with a diagnosis, nor may the family member wish to refer to the PwD as their 'loved one'.

A diagnosis can be a frightening and confusing time and it's important that everyone involved receives the right support. The PwD will have been given information about their diagnosis but what about you? What can you expect in the coming months and years and where can you turn to for help?

## Why are we talking about conflict?

---

It is not uncommon for families to disagree on what kind of care a PwD needs and who should provide it. Often, it falls to one family member to take on most of the responsibility for practical reasons; however, this may not always be in everyone's best interest in the long term. Research shows that if the main carer for a PwD is the spouse or partner, they are more likely to suffer from depression, mental fatigue and a poor relationship. If a parent of yours has dementia and their partner is the primary carer, there is even more reason why siblings need to manage conflict and be united in their support of both parents.

As this guide has been written for families and carers it does not focus on the science behind dementia but discusses how best you can manage or share your caring role, to minimize any conflict that arises amongst family members and – above all – to help you support the PwD in the best way possible. Contact details for organisations mentioned in this guide can be found on the back pages.



## What is conflict and why does it arise?

---

Conflict can be defined as a long, drawn-out argument, a clashing of ideas and opinions. People experiencing conflict can feel angry, frustrated, guilty or hurt. Conflict can start out as a minor disagreement but can quickly escalate into conflict if not resolved to everyone's satisfaction.

Conflict tends to arise when one or more people feel powerless in any given situation. They may feel that they are not being listened to or understood. They may feel that others are ganging up on them or trying to force them to see things another person's way.

When more than one person is involved in making decisions about a PwD's care, it is not uncommon for families to disagree on the type of care that is needed, or the level of care that each individual can or should provide. Historical factors can also affect these decisions. It may be the case that one family member is closer to the PwD or lives nearer; in some cases the eldest child assumes a position of responsibility based solely on their age, which may not sit well with their siblings; or it may be that relationships within the family have a complex history.

Some of the common reasons families or carers disagree over a PwD's care are:

- Carers may feel there is an uneven distribution of the caring responsibilities amongst family members.
- Disagreements arise about whether to retain the family home or sell it to pay for residential care.
- Pressures arising with the primary carer's partner due to caring commitments.
- Homes feeling overcrowded when a PwD moves in.
- Different approaches to managing challenging behaviour.
- Changing roles, e.g. a sibling taking on more of a parental role or just trying to cope with the changes to the relationship with the PwD since the diagnosis.

For some families, only small adjustments need to be made in order for the PwD's needs to be met and for the family to live well. However, if the family is unable to agree on these adjustments, relationships can break down, making it difficult to restore harmony.

In this guide we will look at different challenges that may arise and what you might be able to do to minimize the chances of a disagreement becoming a conflict.





## Understanding and accepting a diagnosis

---

It can be extremely difficult not only for the PwD but also for carers and other close family members to accept a diagnosis. You may feel an array of different emotions whilst coming to terms with this news: sadness, loss, worry, guilt, denial, relief even. All these feelings are perfectly normal and you should feel able to talk these through with other family members who will have their own, perhaps different, set of emotions to manage.

Many people in the early stages of dementia may seem only mildly confused or forgetful. You may feel that they are only displaying behaviours that you would expect from ageing. Dementia is not considered to be a normal part of the ageing process – it is a disease. It's important to trust the professionals who have made the diagnosis, for whilst there is no one robust method of testing, the doctor will consider an array of factors such as previous medical history, medical evidence (usually via a brain scan), changes in the PwD's thinking or behaviours, lifestyle factors, before making their diagnosis.

Conflict can arise when family members disagree on the diagnosis so try to get as much information as you can about the type of dementia the PwD has and how the disease might progress. Dementia UK and Alzheimer's Society have plenty of information on their websites. You may also find that the PwD does not accept the diagnosis, which may be a source of tension between them and their carer(s) as well as between family members who may hold different views.

It is important to remember that everyone who will be involved in the care of the PwD should have an opportunity to have a say in what that care might look like and what contribution they would like to, or are able to, make. If people feel their voice is being heard from the outset it goes a long way to avoiding conflict. **Most of all, whilst the PwD still has capacity to make his or her own decisions, there are plenty of practical things you can discuss with them to smooth the way for the future.**

## First steps

---

Dementia is a deteriorating disease of the brain and each person's journey is different. For some, the disease can progress slowly. For others, particularly with a late diagnosis, the disease can progress rapidly. It is therefore important to discuss the PwD's wishes with them as soon as possible after a diagnosis, whilst they still have Mental Capacity.

### What is Mental Capacity?

The Mental Capacity Act 2005 empowers people to make their own decisions where possible and protects them when they cannot, or are no longer able to make those decisions, within a legal framework. It also allows people to make decisions about their future while they are still deemed able to. If a person is no longer able to make informed decisions for themselves others will be asked to make those decisions on their behalf in their 'best interests', usually a health professional such as a GP. There are 4 main principles which determine a person's mental capacity. These are based on the capacity to understand, retain, evaluate and communicate information given to them.

Conflict can arise when family members disagree on the PwD's 'best interests'. One way to minimize this conflict is for the PwD to appoint one or more attorneys to make decisions on their behalf regarding their future care. We will look at attorneys later in this guide. It is also important to note that a PwD making a decision you consider to be unwise does not necessarily lack Mental Capacity. This may just be because they think differently to you and make different choices.

Another useful conversation to have in the early days is to ask the PwD what they would like to happen to them if they become less able to look after themselves. Do they want certain family members to have specific responsibilities concerning their care or living situation? You might think about encouraging them to write an 'advance healthcare directive', commonly known as a 'living will'.

---

The Advocacy Project in Hackney supports people known to social services to understand their rights, to speak up and to make informed choices. They can also provide Independent Mental Capacity Advocates (IMCAs) who can represent the PwD when they are deemed to no longer have Mental Capacity.



## The Living Will

---

The advance care directive, or living will, allows a person with Mental Capacity to decide what kind of care and treatment they want as the dementia progresses. It is a legally binding document which allows the PwD to choose whether or not to receive life-saving treatment such as CPR (Cardiopulmonary resuscitation) or antibiotics. It does not allow them to choose to be denied food or water.

Living Wills are free to write and can be downloaded from the internet, though they must be signed by the PwD and witnessed.

A living will can give a clear indication to family members and those caring for them, what kind of care the PwD would like, where feasible. Alzheimer's Society and Age UK have very good guidance around this on their website. Advance statements include requests such as whether a person prefers to have a bath or a shower, what they like to eat and drink (and at what time), what time they like to go to bed/get up, whether they have any religious beliefs they would like people to be aware of. Just because a person has lost capacity it doesn't mean they are necessarily no longer aware of what is happening around them. Keeping someone's habits and rituals in line with their wishes can be very helpful in keeping them calm and content.

## Lasting Power of Attorney (LPA)

---

(Enduring Power of Attorney in Northern Ireland for financial matters only)

LPA is a legally-binding document which enables the PwD to choose a person or persons who will take responsibility for decisions around their care, property and finances, once they can no longer make decisions for themselves.

There are 2 types of LPA:

- health and welfare
- property and financial affairs

LPAs come into effect as soon as someone is deemed to no longer have Mental Capacity (as assessed by a health professional such as a GP following the 4 principles as outlined in the previous chapter) and ceases to have any value at the point of death, when the Will comes into effect and the power to take action passes to the executor(s). Anyone who has property or assets, or who wants someone to act in their best interests in terms of their healthcare, should apply for LPA.

There is plenty of information online about how to register as an attorney. The Government website gives details of how to apply and costs involved (discounts are available to those on benefits). Contact details of organisations who can help can be found at the back of this guide.

The person making a LPA (known as the donor) should be supported to consider and decide who they deem to have their best interests at heart. It is usual to have more than one attorney (2 is common). This decision may in itself cause conflict if family members disagree with the PwD's decision or if they believe the PwD may have been influenced by others. If you feel a PwD has been pressured into appointing an Attorney who you feel may not have the PwD's best interests at heart you may wish to consider contacting City or Hackney's Adult Safeguarding Teams for further guidance.

One thing to bear in mind, attorneys can be appointed both jointly and/or severally. If you are helping a PwD decide which to choose it is important to understand the distinction as this can often lead to unnecessary disputes at a later date. If attorneys hold LPA jointly it means that all the attorneys must agree when making a decision whereas severally means that one individual may act on their own without the other attorneys. It is possible for the donor to choose that some decisions be made jointly while others can be made severally.

It can be difficult for families to broach the subject of LPA and Living Wills so you might find it helpful to have another family member, or a close friend of the PwD, present to raise the subject.

You will also find that arranging LPA earlier rather than later gives you a good indication as to the PwD's financial status which will help you to talk to them about any preferences in regards to paid care, if required, in the future.





## Sharing the load

---

Let us assume that after the PwD has received their diagnosis they decide they want to remain independent in their own home for as long as possible. What does this mean for family members/carers?

The PwD needs to be supported to continue their life as uninterrupted as possible, as long as they are safe and the support they need to do this can be provided. A PwD is likely to manage day-to-day life better in familiar surroundings and with familiar routines so this should be weighed up with the practicalities for all concerned in their care. Conflict can arise when the environment ceases to be a practical option, and family members disagree that independent living is in the PwD's best interest. Likewise, if family members are scattered around the country (or world) it may not be possible for everyone to do their fair share. How do you avoid conflict in this situation?

Often one family member assumes the responsibility of primary carer. This may not be the best arrangement however. It may be advisable to hold a family meeting (with the PwD if possible) to decide who can take on different tasks such as arranging appointments, collecting medication, shopping, housework, laundry, check-in phone calls. Try to spread the load where possible and remember that the primary carer needs to have a break from caring and support to live their own life alongside their caring role. Family members who live far away can still help with tasks such as a daily phone call to check the PwD has eaten and is safe and well. They might also be able to make a financial contribution towards paid care or respite care to give the primary carer a break and prevent the caring arrangements from breaking down. Think about a rota for weekend visits. Can shopping be ordered online and delivered to the PwD? Can you access some outside help? Hackney and the City have several befriending services and you may want to discuss this with the PwD so that they can have regular visits from someone outside of the family to ease some of the pressure.



## The Circle of Support

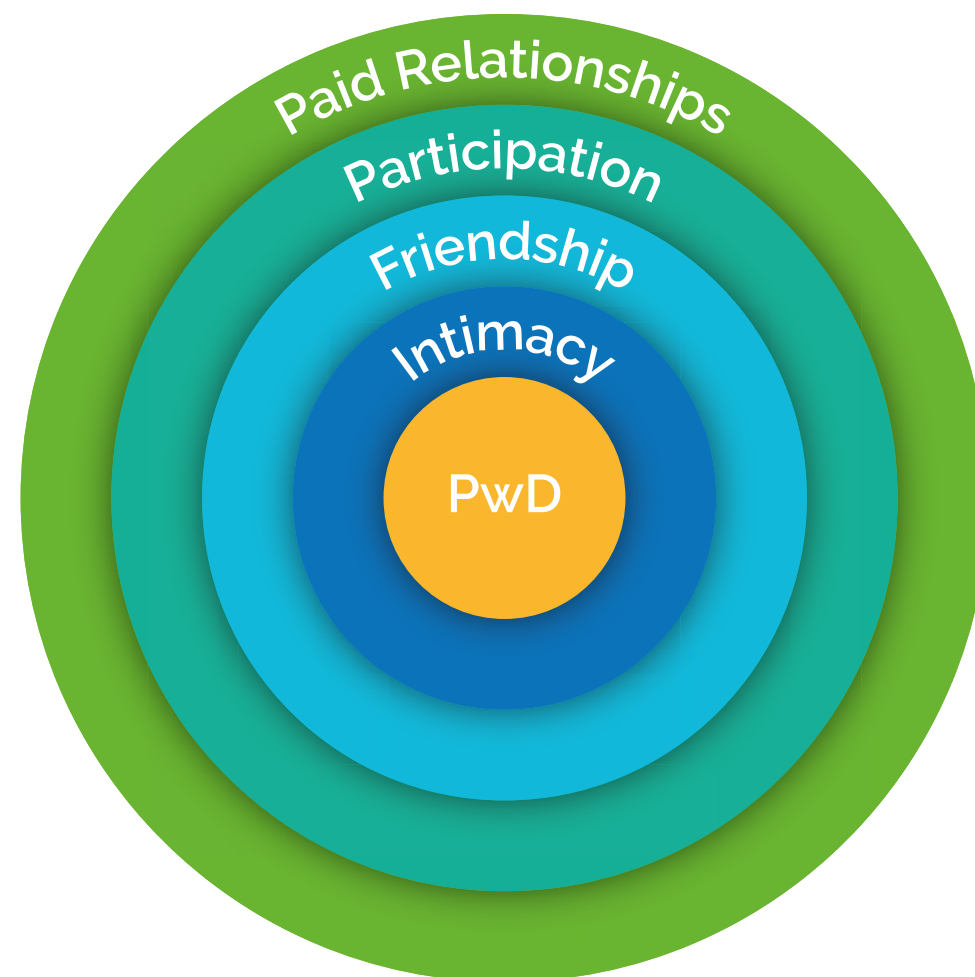
---

You may find it useful to create your own Circle of Support for the PwD. This can be helpful when allocating responsibilities to various family members and friends. You can include as much or as little information as you want. The circle can also act as a diary, showing who visits the PwD at set times of the week. Remember to include contact details in case of an emergency. The Metropolitan Police run a scheme called the Herbert Protocol. Register the PwD's details using a simple online form. In the event that the PwD goes missing you can hand the form to the investigating officer.

The PwD is always at the centre of the Circle of Support. Immediately around the PwD are those closest to them, namely the spouse/partner, children, best friend. This is the **intimacy** circle. The **friendship** circle could include close friends and extended family. Those with shared interests with the PwD might be included in the **participation** circle: colleagues from social clubs and committees, neighbours. You might also like to include people that the PwD has got to know in their local community who they see on a regular basis, such as the local shopkeeper or publican. Finally, the **paid relationships** circle should include the PwD's GP, district nurse, agency carers, local cab firm, care coordinator. It is particularly useful to include this groups' contact details.

It's a good idea to keep a written log in the PwD's home so that anyone from the Circle of Support can record details of their visit. You might like to keep a list of phone numbers in the coat pocket or Freedom Pass wallet of the PwD so that if they get into difficulty someone from the Circle of Support can be contacted.

You might want to ask the PwD's care team about other resources available locally, such as Telecare (where the PwD is given a pendant or bracelet to wear which is connected to a phone line).





## Conflict arising from behavioural or psychological symptoms of dementia

---

Dementia can bring about a variety of changes in the PwD which can be as confusing and upsetting for you as it is for them. How family members or carers react to this can have the effect of either soothing or inadvertently distressing the PwD, which can lead to conflict. It is not uncommon for a PwD to feel mistrustful of people around them, however close the relationship. This may be due to gaps in their memory which then distorts their reality. If you can help them to fill these gaps you may find that the trust returns. They may be confusing an event in the past with the present. It's important for everyone involved in a PwD's care to understand this and accept it. It can be frightening for a PwD if they are told that what they are saying isn't true/didn't happen. It may be that it did happen at some time in their life, and this is where their memory is currently focussed. It might help to try to change the subject or find a distraction.

Some common behaviours in a PwD might include:

- becoming confused, agitated or aggressive (sundowning)\*
- using repetitive language
- resisting help with personal care
- experiencing hallucinations or false beliefs
- walking away, for example, leaving the house
- getting up constantly in the night to look for things
- forgetting how to perform simple tasks
- misplacing items and accusing people of stealing

\* *Sundowning is a symptom of Alzheimer's disease and other forms of dementia. It is also known as "late-day confusion". If someone you care for has dementia, their confusion and agitation may increase in the late afternoon and evening.*

If you find you are struggling with this sort of scenario, you might find it helpful to follow these basic rules:

- Don't ask direct questions
- Listen to the expert – the PwD – and learn from them
- Don't contradict what the PwD says
- Find a conversation or activity to distract the PwD from their anxiety/repetitive behaviour
- Look for a reason behind their behaviour or feelings. If they continually repeat themselves consider how you might help them to find the answer they might be looking for

A PwD's GP might prescribe anti-psychotic drugs, anti-depressants or anti-anxiety medication to relieve some of the symptoms but these can cause side-effects which can be just as difficult to manage as some of the behaviour.

There is much evidence to suggest that sensory stimulation such as music, dancing or gentle hand massage can be helpful in reducing anxiety and agitation.

Please refer to Alzheimer's Society and Dementia UK's websites for further reading on symptoms and behaviours.



## Conflict outside the family

---

There are over 1,800 people living with dementia in Hackney and the City, and, as with most other illnesses or diseases, resource demands in health and social care are extremely high. In day-to-day terms this can mean long waiting lists, appointment cancellations due to staff shortages, delays in hospital admissions due to restricted access to beds, limited places in day centres or for respite care. All these factors contribute to families feeling, at times, anxious and unsupported. It can also create extra work for families already stretched by their commitments. If you feel that you are not being listened to by health professionals, or that they are not acting upon your wishes or in the best interests of the PwD, you may be eligible for support from The Advocacy Project. Mind, the mental health charity, provides a Citizens Advocacy service for those not eligible to access the Advocacy Project. POhWER, a Hackney-based charity, provides Independent Mental Capacity Advocates (IMCAs), for both City and Hackney residents, who can represent the PwD in any decision-making process. The Social Care Institute for Excellence (SCIE) has very clear information about the role of an IMCA. If you wish to make a formal complaint with regards to healthcare, you can do so through the Patient Advice and Liaison Service (PALS) or, if you are a Hackney resident, through POhWER's Independent Health Complaints Advocacy Service (IHCAS). For complaints pertaining to social care, you can contact London Borough of Hackney and City of London in a number of ways.

Families may focus their stress on other family members – it can be easier than doing battle with others outside the family. Occasional conflict is part of normal family life but when it remains unresolved it can be exhausting and upsetting for all involved. A family in conflict can make the job of health professionals difficult if there is disagreement about the best care or environment for the PwD. If you experience such a situation, try to put the PwD's best interests first, before your own. It is advisable for the primary carer to register with their local carers service as soon as a PwD receives their diagnosis so that they can be signposted to the most appropriate organisation if and when a problem arises.

## Resolving conflict

---

The key to resolving a family conflict is communication and empathy. We need to try to remember that people may be under a lot of pressure and try to think about the type of language we use in a conflict situation, the tone of our voice and our body language.

It is not uncommon for family members to experience feelings of guilt when caring for a PwD. As the disease progresses, the care needs and challenges increase; the PwD may forget who some family members are or get them muddled with family members long since deceased. Admitting that you can no longer cope, or that the PwD might be more settled in a care home, can cause those feelings of guilt to spill over into resentment towards other family members, particularly if they have suggested you might need professional support which they are not able to provide. It's important to get the balance right between the needs and wishes of the PwD, your own needs and wishes, and the level of nursing care that might be needed.

You can use the conflict chart in the middle pages of this guide to think about how a difficult situation is affecting you and how you might be able to cope with it. Below are some suggestions for trying to work through conflict constructively:

### 1. Clarify your thoughts and feelings.

It might help to write some things down before attempting to talk to the other people involved in the conflict. Writing things down can be a therapeutic process; it helps you to find some clarity in your thoughts and feelings, for example:

- What am I upset about and how did it start?
- What did the other person say to me that made me feel upset?
- Did I say anything back to them that might have been hurtful?
- How am I feeling?

- 
- How do I think the other person might be feeling?
  - What outcome would I like to achieve by talking to the other person?
  - Might I have to make some compromises? If so, what might they be?

## **2. Try to be constructive and focus on solutions rather than problems.**

It may help you to discuss what you can all do to keep the conversation respectful and helpful to both parties before you start.

- Practice out loud some of the things you want to say. Pay attention to the tone of your voice and the words that you use. Try not to say things like “You made me look really stupid in front of the consultant the other day”, rather “I felt my views weren’t being taken seriously by you and the consultant the other day”. Take responsibility for how you felt, rather than putting the onus on how the other person made you feel.
- There may be a number of things that have irritated you but try to resolve one thing at a time. If you bombard the other person with a list of complaints about their attitude or behaviour they will feel under attack and either attack back or withdraw into silence.
- Rather than focussing on what went wrong and looking for someone to blame, think about what a good outcome or solution would be and how you could work together to achieve it.

---

## **3. Think about how to manage the meeting to get the best outcome**

You might like to think about a suitable meeting place where there are few distractions. Think about where it would be convenient for the other person to meet. If they feel they are having to go out of their way to come and meet you that might create an imbalance of power before you have even met up. Pick a time when you are not over-tired or stressed.

## **4. If all else fails, seek help**

Try talking to someone else to get a different perspective to help you work out how best to manage the situation. Your local carers service can signpost you to organisations who offer counselling and life coaching.

A number of organisations offer Mindfulness or meditation, workshops helping to reduce stress or insomnia, support groups and information sessions. Most are free and can be found on Hackney i-Care, in Hackney Today (free newspaper) or via leaflets in libraries and GP surgeries across both boroughs.

If you are worried about your own or someone else’s wellbeing you will find phone numbers for the Samaritans and Adult Safeguarding Teams for the City and Hackney listed at the back of this guide.

Carers sometimes find it difficult to ask for help as they worry that if health professionals think they are not coping, the PwD will be taken into care. This kind of decision is not taken lightly. The best option for the PwD is to be living at home, as long as they are safe and their needs are being met. If you feel you can no longer cope, try to keep an open mind about other housing options available to the PwD. It’s a good idea to have a look around some of the sheltered housing schemes or ‘housing with care’ placements sooner rather than later so that you can make informed decisions, particularly if the PwD has specific religious or cultural needs.



## Where to get help for yourself

---

### Practical and emotional support

People seek help from different sources. Some are happy to be supported by family, friends and their immediate community; others might not wish to share feelings and concerns with people close to them so seek confidential, non-judgemental support elsewhere. Some don't seek help at all and soldier on with little or no support. Keeping feelings of confusion, anger and helplessness to oneself can lead to burn out, which can impact on how patient and caring we are towards the PwD.

There is a good network of support for family members and carers living in the City and Hackney. It's helpful to research the various organisations before you need their help so that you can act quickly if you find yourself in crisis. People of different faiths have different sources of support. For you, it might be more appropriate to ask extended family to mediate rather than an Imam, Rabbi, Priest or Elder. Try to think about who you might go to for support before you find yourself in a difficult situation; conflict can often cloud our vision and make it difficult to make rational decisions.

Make sure your GP knows about the recent changes in your circumstances. They may have useful information to share with you. The PwD will be under the care of their own GP until such times as their needs become more complex. At this point, their GP can refer them to the Older People's Community Mental Health Team. The PwD may also be referred to Adult Social Care who will assess their physical needs and arrange a care package for them, if required. This might include agency carers visiting once or twice a day to support the PwD with their personal care, or to make sure they have something to eat.

City and Hackney Carers Centre (CHCC) has been supporting carers for over 20 years. Their main focus is to support the carer, rather than the person who is being cared for. CHCC offers benefits and housing advice, support groups, counselling and coaching, workshops and training, day trips. They also offer an online learning

and support group, "Dementia Discussions" to help equip you with the tools, knowledge and support to thrive in your caring role.

Alzheimer's Society City and Hackney offers people with a diagnosis of dementia and their carers an allocated Dementia Navigator who will provide information, advice, support and signposting to help you navigate the health and social care system. They run dementia cafes, Singing For The Brain™ and support and training. Nationally, this organisation offers an online community both for people living with dementia and their carers.

Age UK East London provides information and advice around benefits, charitable grants, housing and care. They have a non-statutory advocacy service in Hackney and can arrange for a (paid) home help to assist with shopping and cleaning.

Bikur Cholim runs a monthly support group for Orthodox Jewish people caring for a PwD. They also offer counselling.

Dementia UK is a national organisation which publishes factsheets to help you understand more about the disease and to manage your caring role. You can also watch their Admiral nurses online offering advice and support and speak to them directly on the helpline.

"Talk Changes" (formerly Primary Care Psychology) offers interventions for stress, low mood, anxiety and other common emotional problems. You can also self-refer to this service. You can also find authorized private practices through the British Association for Counselling and Psychotherapy's directory. If the PwD is open to the Older People's Mental Health Team psychological interventions are available which can include families and carers, for example, to develop behavioural strategies to help you cope at home.

Mind in the City, Hackney and Waltham Forest offer a range of wellbeing activities to help relieve the daily stress of caring. They also offer advice and support around welfare rights and benefits.

The North London Muslim Community Centre offers welfare and benefits advice, form-filling (including LPA), support for carers (informal listening ears rather than counselling from qualified therapists) and family mediation.

## Financial support

Additional caring can put a burden on a family and lead to arguments and resentful feelings. It can also put a strain on someone's finances if they are spending extra money on travel expenses or time away from work.

The person giving the most of their time to provide care is called the primary carer. If they are not working, or earning less than £120 per week (current figure set for 2018-19) they may be eligible to claim Carers Allowance. Although the amount is nominal it can help with travel expenses. Even if the primary carer is working they may still be struggling financially so they may need additional financial support from family members or an allowance from the PwD's funds, to be agreed with the Attorneys.

The primary carer should also register with the local carers service in the borough where the PwD lives. This service will be able to help you access a benefits check both for you and the PwD. People with care needs may be eligible for a non-means tested benefit.



## Useful contacts

### Colour Key

**Hackney**

**City**

**City and Hackney**

### ADVICE (housing, benefits, welfare rights) and LEGAL MATTERS

#### Age UK East London

<https://www.ageuk.org.uk/eastlondon/>

020 8981 7124

National Helpline: 0800 055 6112

#### Bikur Cholim (Orthodox Jewish)

<http://bikurcholim.co.uk/>

020 8800 7575

#### Citizens Advice Bureau

Hackney: 020 8525 6350

City: 0344 826 9699

#### Derman (Kurdish, Turkish, Turkish Cypriot)

<http://derman.org.uk/derman/>

020 7613 5944

#### Hackney Community Law Centre

<https://www.hclc.org.uk/>

020 8985 5236

#### Hoxton Trust

<https://www.hoxtontrust.org/>

020 7729 1480

#### Lasting Power of Attorney

<https://www.gov.uk/power-of-attorney>

#### Living Wills

<https://www.ageuk.org.uk/>

### **North London Muslim Community Centre**

<https://www.nlmcc.org.uk/>  
020 8806 1147

### **Toynbee Hall**

<http://www.toynbeehall.org.uk/>  
020 7392 2919

## **ADVOCACY AND COMPLAINTS**

### **The Advocacy Project**

<https://www.advocacyproject.org.uk>  
020 3960 7920

### **Citizens Advocacy Project (run by Mind in CHWF)**

[www.mindinhackney.org.uk](http://www.mindinhackney.org.uk)  
020 8525 2301

For residents not eligible for statutory advocacy.

### **Complaints (Health and Social Care, City and Hackney)**

<http://www.cityandhackneyccg.nhs.uk/>  
020 3816 3222

### **Patient Advice and Liaison Service (PALS)**

<http://www.homerton.nhs.uk/>  
020 8510 5555

To make a complaint:

0800 085 8354

[palsandcomplaints@elft.nhs.uk](mailto:palsandcomplaints@elft.nhs.uk)

### **POhWER**

<https://www.pohwer.net/hackney>  
0300 456 2370

Independent Health Complaints Advocacy for City and Hackney residents who wish to make a complaint about treatment provided under the NHS. Statutory advocacy service for City residents.

### **Social Care Institute for Excellence**

<https://www.scie.org.uk/>

Clear information about the role of an IMCA.

## **BEFRIENDING**

### **Age Concern**

<http://ac-cityoflondon.org.uk>  
020 8981 7124

### **Compassionate Neighbours**

<https://www.stjh.org.uk/neighbours>  
020 8525 6058

## **CARERS SERVICES**

### **Age UK East London**

<https://www.ageuk.org.uk/eastlondon/>  
020 8981 7124

### **Carers Allowance**

<https://www.gov.uk/carers-allowance>  
0800 731 0297

### **Carers Trust**

<https://carers.org/>

Umbrella organisation providing information on the national network of carers services.

### **Carers UK**

<https://www.carersuk.org/>

Online forum for carers to support each other.

### **City and Hackney Carers Centre**

<https://www.hackneycarers.org.uk/>  
020 8533 0951

### **City Carers Service**

<https://carers-network.org.uk/information/city/>  
020 8960 3033

### **NHS Choices: Carers Direct**

<https://www.nhs.uk/>  
0300 123 1053



## St Joseph's Hospice Friends and Family Peer Support Group

<https://www.stjh.org.uk/>  
020 8525 3140

### EMERGENCY NUMBERS

#### Adult Social Care

[adultsduty@cityoflondon.co.uk](mailto:adultsduty@cityoflondon.co.uk)  
020 7332 1224 (weekdays only)  
Weekdays after 5pm, weekends and bank holidays: 020 8356 2300

#### Adult Social Care

<https://www.hackney.gov.uk/>  
020 8356 6262 (weekdays only)  
Weekdays after 5pm, weekends and bank holidays: 020 8356 2300

#### The Herbert Protocol

Call 999 and hand the visiting officer the completed form which you can download here:  
<https://www.met.police.uk/herbertprotocol>  
If non-urgent, call 101.

#### Safeguarding Adults Team

<https://www.cityoflondon.gov.uk/>  
020 7332 1224  
020 8356 2300 (out of hours)

#### Safeguarding Adults Team

<https://hackney.gov.uk/>  
020 8356 5782  
020 8356 2300 (out of hours)

### HELPLINES AND ONLINE FORUMS

#### Alzheimer's Society

<https://www.alzheimers.org.uk/>  
National Helpline: 0300 222 11 22  
Hackney: 020 8533 0091

#### CALM (Campaign Against Living Miserably)

[www.thecalmzone.net](http://www.thecalmzone.net)  
0808 802 5858

#### Dementia UK

<https://www.dementiauk.org/>  
Freephone: 0800 888 6678  
Advice and support for you and the PwD from an Admiral (specialist dementia) nurse.

#### Independent Age

<https://www.independentage.org/>  
0800 319 6789

#### The Samaritans

<https://www.samaritans.org/>  
Freephone: 116 123  
Trained volunteers available at the end of a phone 24 hours a day  
365 days of the year.

### THERAPEUTIC SUPPORT

#### British Association for Counselling and Psychotherapy

<https://www.bacp.co.uk/>

#### Centre for Better Health

<http://www.centreforbetterhealth.org.uk/>  
020 8985 3570  
Offers a wide range of therapeutic approaches plus courses in health and the creative arts.

#### Hackney Recovery Service (drug and alcohol support)

<http://hackneyrecovery.org.uk>  
Freephone: 0300 303 2611  
Out of hours: 0808 168 8669

#### Mind in the City, Hackney and Waltham Forest

<https://www.mindhackney.org.uk/>  
020 8525 2301

### **Square Mile Health (drug and alcohol support)**

<http://www.squaremilehealth.org.uk/>  
0300 303 2715

### **Talk Changes (formerly Primary Care Psychology)**

[www.talkchanges.org.uk](http://www.talkchanges.org.uk)  
020 7683 4278

Self-refer for an assessment or online treatment.

### **The Tavistock and Portman NHS Foundation Trust**

<https://tavistockandportman.nhs.uk/>

Family and individual therapy available via a GP referral.

### **Vietnamese Mental Health Services**

<http://www.vmhs.org.uk/>  
020 7234 0601

Advice, support and counselling for the Vietnamese and Chinese communities.

## **OTHER USEFUL CONTACTS**

### **City Memory Group**

<http://www.toynbeehall.org.uk/>  
020 3857 8668

Activities and outings for people concerned about their memory.

### **Dial-a-Ride**

<https://tfl.gov.uk/modes/dial-a-ride/>  
0343 222 7777

A free door-to-door service for anyone who has difficulty using public transport.

### **Hackney Caribbean Elderly Organisation**

<http://home.btconnect.com/hceo.org.uk/>  
020 7923 3536

Lunch clubs, exercise and memory club

### **Hackney i-Care**

<https://www.hackneyicare.org.uk>  
Hackney's online services directory.

### **LGBT+ Carers Support Group**

[www.lgbt@hackneycarers.org.uk](http://www.lgbt@hackneycarers.org.uk)  
020 8533 0951

### **London Gypsies and Travellers**

<http://www.londongypsiesandtravellers.org.uk/>  
020 8533 2002

Older People's Community Mental Health Team  
020 3222 8500

### **Taxicard**

<https://www.londoncouncils.gov.uk/services/taxicard>  
Reduced cab fares for people claiming higher rate mobility component for DLA or PIP.

### **Unforgettable**

<https://www.unforgettable.org/>  
Online store selling products to help people with dementia in their daily lives.

**Sponsored by**  
City and Hackney Dementia Alliance

**Written by**

Sallie Fellowes for City and Hackney Carers Centre, with special thanks to Dr Tessa Fulton, Clinical Psychologist, Diagnostic Memory Clinic, East London Foundation Trust, Steven Reading, Dementia Support Manager, Alzheimer's Society City and Hackney, Catherine Macadam, Coach, Mentor, OD consultant, Christian Forssander, Human Givens therapist, City and Hackney Carers Centre.

First published April 2019. Version 1.



City and Hackney Clinical Commissioning Group  
East London NHS Foundation Trust  
Homerton University Hospital Foundation Trust



City & Hackney Carers Centre



St Joseph's  
Hospice