

**Carers  
Crisis  
Toolkit**

**Welcome to the Dementia Discussions!**  
This service has been developed to support carers of people with dementia like yourself. Caring for someone with dementia can be frustrating and can make you feel like you're on your own. You may find yourself struggling to cope with the demands of your caring role. Our aim is that this toolkit will be able to equip you with the skills, knowledge and support to thrive within your caring role. You can choose to use this toolkit alone, with input from family, friends, your GP or other professionals; it's totally up to you.

**Dementia**  
Discussions



## Introduction

In the UK there are an estimated 850,000 people diagnosed with dementia. The vast majority of these people live at home in the community, cared for by family members and friends. Caring for a person with dementia (PwD) is not always an easy task and we understand that your caring role comes with its own complex challenges and set of needs unique to the person with dementia.

As a carer for a PwD you may find yourself struggling to find information about the condition, identifying the people best placed to support you in your role, managing any challenging behaviours if they occur and making time to look after your own health and wellbeing. This may cause you to experience periods of stress or anxiety, which might make you feel stuck or helpless.

This toolkit has been designed to help carers of PwD during times of crisis or those moments where you are struggling with the person you care for. We hope that this toolkit will provide you with the confidence, skills and strategies to better cope within your caring role.

In moments of crisis, many people find it hard to think clearly. This is especially true for carers of PwD who may have additional challenges such as communication difficulties, dual diagnoses (a dementia diagnosis plus an additional illness or disability), and dealing with possible challenging or unpredictable behaviours. This is why it is a good idea to think ahead and to map out your own individualised action plan when things are calmer and you have the chance to consider all options. Writing your plans down is a good way to make sure you know what to do in an emergency and provides you with a practical tool that you can refer back to when you are unsure, or struggling to remain calm in challenging situations.

You can choose to keep this toolkit to yourself or you can share it with other people who are involved in the PwD's life such as family, paid carers or health professionals - remember to get the PwD's consent (when possible) if you choose to involve others because your decisions will ultimately have an impact on the PwD.

It is important to try to include the PwD as much as you can, and give them a voice. This toolkit can be used to develop strategies for supporting the PwD and to make sure that their needs are met to best of your abilities and as safely as possible. More so, it can help you become more confident within your caring role and ensure that your needs are also being acknowledged and addressed. It is so important for you, as a carer, to take care of yourself so that you can continue to take care of the PwD.

# Dementia Journey

"I've just been feeling so lost – I don't know what to expect to happen. There is so much information out there but it's scattered. I just wish I knew the basics..."

The word dementia is an umbrella term that is used to describe a set of symptoms that arise from physical damage to the brain caused by diseases such as Alzheimer's disease and Parkinson's disease, or by physical trauma such as a series of strokes. Symptoms will differ depending on the source of damage and which part of the brain are affected, they can include memory loss, difficulties with decision making, problems communicating and for some, changes in personality and mood. There are over 100 different types of dementia.

The most common are:

## 1 Alzheimer's disease

This is the most common type of dementia. Between 60 to 80% of cases of dementia are caused by this disease. It causes brain cell death through the build-up of proteins (referred to as) plaques and tangles on brain tissue. These protein build ups interrupt or block the connections between nerve cells. Because Alzheimer's is a progressive disease, as the protein build-ups get bigger over time and symptoms will worsen as the person passes through the mild and moderate to the severe stages of the disease.

Early symptoms of Alzheimer's disease tend to include low mood, forgetting names and recent events; as time goes on additional symptoms such as memory loss, problems with communication, reasoning and orientation may occur. In the final stages the PwD will be much less aware of what is happening around them. They may have difficulties eating or walking without help, and become increasingly frail.

## 2 Vascular dementia

Vascular dementia, the second most common form of dementia, accounts for approximately 10% of cases. It is caused by conditions that either block or reduce blood flow to the brain depriving it of oxygen and nutrients which lead to brain cell death. There are various forms of vascular dementia: single-infarct and multi-infarct dementia, subcortical dementia and mixed dementia.

Symptoms of vascular dementia are dependent on which area of the brain is damaged. Generally the abilities to think and reason are affected first; with memory loss occurring at later stages. Common symptoms of vascular dementia include problems with planning, organisation, following commands or directions; people will also experience issues concentrating accompanied by periods of sudden confusion. The PwD may also have frequent mood swings and depression. In later stages severe confusion or disorientation, memory loss and further problems with reasoning and communication are common.

## 3 Dementia with Lewy bodies and Parkinson's disease dementia

Dementia with Lewy bodies (DLB) accounts for about 4% of dementia. It is caused by the build-up of tiny protein deposits (AKA Lewy bodies) in the nerve cells of the brain. Lewy bodies are also the cause of Parkinson's disease. The location of the Lewy bodies partly determines how someone is affected. Lewy Bodies closer to the base of the brain are linked to problems with movement and Lewy Bodies in the outer layers of the brain are linked to cognitive symptoms.

Everyone is different, but the PwD will usually have some of the symptoms of Alzheimer's disease and some of the symptoms of Parkinson's disease. They will also have some symptoms which are unique to Lewy Bodies. Visual hallucinations, problems with movement, sleep disturbances and problems with alertness and attention span are all common. As with other dementias, symptoms will get worse over time and become similar to that of Alzheimer's. It is normal for a person with DLB or Parkinson's disease dementia to require home nursing care and support in the later stages.

## 4 Frontotemporal dementia

This type of dementia impacts the lobes of the brain behind the forehead (frontal lobes) and the lobes on the sides of the brain (temporal lobes). The dementia occurs when the nerve cells in the frontal and/or temporal lobes of the brain die and connections between the lobes change. As time passes more and more nerve cells die, causing the brain tissue to shrink. It's the damage to these lobes that determines the symptoms. For this type of dementia common symptoms include changes in personality (loss of inhibitions, interests, empathy/sympathy), behaviour (developing obsessive or repetitive rituals, craving unhealthy foods), and difficulties with language (slowed speech, errors in grammar, word searching). Frontotemporal dementia is the most common form of dementia for younger people (those under 65). There is a genetic link to this type of dementia so if you have a family history of this type of dementia, you may want to have a genetic test done to see if you are at risk. As with most types of dementia, a person's life span varies and it is difficult to predict. People with this condition can become easily socially isolated as the disease progresses because they may not want to spend time in the company of others, or behave in ways others find challenging.

## 5 Creutzfeldt-Jakob disease (CJD)

It is the most common human form of a group of brain disorders referred to as prion diseases. It occurs when prion proteins within the body begin to change shape and fold into an abnormal three-dimension shape. This triggers the prion proteins in the brain to fold into the same abnormal shape. CJD can be classified as sporadic (developing spontaneously), familial (certain changes to chromosome 20 gene coding) or acquired (eating meat or products from cattle who are infected with "mad cow disease")

This destruction of brain cells causes decline in thinking and reasoning as well as involuntary muscle movements, confusion, difficulties walking and mood changes. This form of dementia is rare and progresses unusually fast in comparison to those we have already covered.

## 6 Mixed dementia

Is a condition where more than one type of dementia exists simultaneously in the brain, changes to the brain and symptoms reflect the different forms of dementia. The most common combination is Alzheimer's disease and vascular dementia- the plaques and tangles associated with nerve cells in Alzheimer's disease are present alongside the blocks that cause reduced blood flow in vascular dementia.

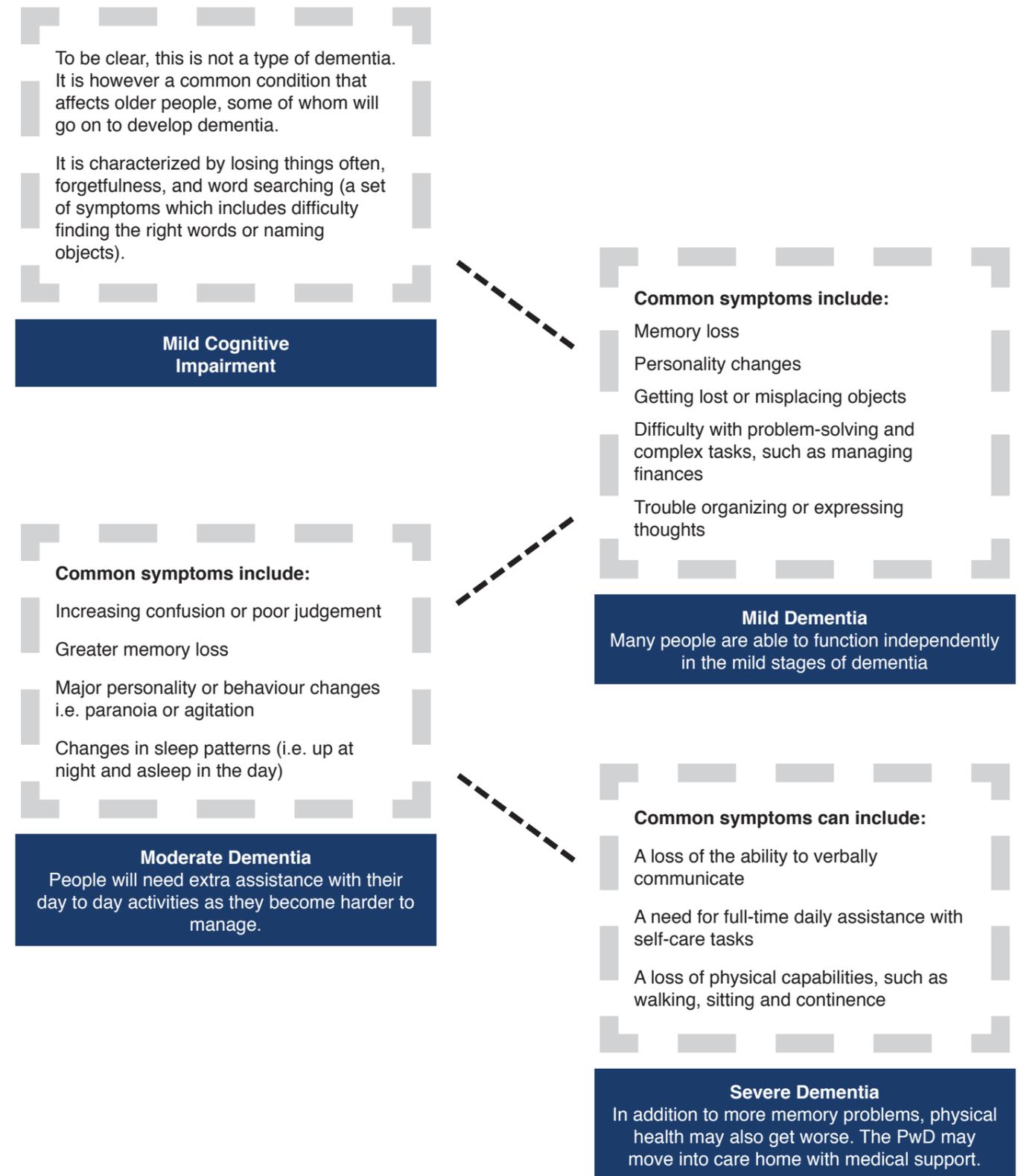
Other forms of mixed dementia include: Alzheimer's disease and DLB/Parkinson's disease dementia wherein the plaques and tangles of Alzheimer's exist alongside the Lewy bodies. In some cases a person can present with symptoms linked to Alzheimer's disease, vascular dementia and DLB.

## 7 Huntington's disease dementia

Huntington's disease is an inherited condition that damages certain nerve cells in the brain and causes abnormal movements and problems with coordination. The age of onset and the course of the disease varies for each person, and dementia can occur at any stage of the illness. The symptoms of Huntington's disease dementia can include difficulties with concentration, planning and organisational skills and a loss of short-term memory. This form of dementia differs from Alzheimer's disease in that those affected continue to recognise people and places until the very late stages of the illness.

## Road Map:

It should be noted that the dementia journey is unique to each individual and depends greatly on the underlying cause of their dementia. There are certain symptoms that are common for most people with dementia. These are outlined below in relation to the condition's progression.



The average dementia journey from diagnosis lasts approximately 10 years with some exceptions (CJD). It is important to note that this is an estimate, and there are many factors that play into life expectancy such as other conditions or illnesses and general physical health. Regardless, it is important for you as carers to plan ahead and to develop strategies, techniques and mechanisms to help you cope within the role and care for the PwD to the best of your abilities.



# Personal Profiles

“I struggle sometimes to think about who we were before the diagnosis. Our lives have become all about appointments. He is the patient and I am the carer, not he is the husband and I am his wife. I miss us.”

Throughout the toolkit you will be exploring ways to better manage and cope with crises related to the PwD. By putting together a personal profile of the person you care for it may help you to better understand why they behave or act as they do. The profile is important and you will refer back to it whilst completing other sections of this toolkit, section C in particular where we look into how to cope with challenging behaviours and related crises.

In this section we also ask you to put together a brief profile of yourself – after all you are a person first, and a carer second. Putting together a profile about yourself will help you to reconnect with who you are beyond your caring role. This will be useful when we discuss coping techniques later on.

## PwD Demographics:

The name of PwD is: \_\_\_\_\_

The age of PwD is: \_\_\_\_\_

The gender of PwD is: \_\_\_\_\_

My relationship to the PwD is: \_\_\_\_\_

PwD Diagnosis: \_\_\_\_\_

The person I care for has a diagnosis of \_\_\_\_\_ dementia

In addition to their dementia diagnosis the person I care for also has:

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

## Checklist:

This checklist can help to identify the activities that the PwD can accomplish. Not all of the items on this list may be applicable to your cared for person's situation. This check list also identifies the amount of support that is needed to each activity and how you as a carer support the PwD.

	Needs help all the time	Needs some help	Can do it him/herself
<b>PERSONAL SKILLS</b>			
Use a spoon			
Use a knife and fork			
Brush his/her teeth			
Comb his/her hair			
Dress him/herself (in appropriate clothing)			
Take a shower or draw a bath			
Groom him/herself (shaving, makeup, styling hair, etc)			
Use the bathroom			
Walk around the block			
<b>Notes:</b>			

	Needs help all the time	Needs some help	Can do it him/herself
<b>DOMESTIC &amp; SHOPPING SKILLS</b>			
Take out the rubbish			
Make the bed			
Put dirty clothes into the laundry basket			
Wash his/her clothes			
Vacuum			
Sweep the floor			
Do the washing up			
Dust or wipe down the table			
Make a shopping list			
Know that money has value and understand denominations			
Choose appropriate and/or healthy foods			
Know his/her clothing size			
Be able to purchase items with money			
<b>Notes:</b>			

	Needs help all the time	Needs some help	Can do it him/herself
<b>COMMUNICATION SKILLS</b>			
Speak, using complex phrases			
Speak, using simple phrases			
Write a letter or note			
Use a mobile phone or landline to make a phone call			
Use a mobile phone to text or Whatsapp			
Use a computer to navigate the internet, take part in an online community or play games			
Visit and talk with friends and family			
Be able to request help dialling '999' or '111'			
<b>Notes:</b>			

	Needs help all the time	Needs some help	Can do it him/herself
<b>COMMUNITY ACTIVITIES &amp; TRANSPORTATION</b>			
Go out for a meal			
Attend a play, concert or cinema for the full duration			
Attend religious services			
Attend community events (i.e. weddings, ceremonies)			
Exercise or participate in sport			
Work at a paid or volunteer job			
Walk, use a trolley or push a wheelchair			
Ride in a car			
Take the bus			
Take the tube or a train			
Be able to read and understand the bus schedule			
Be able to fly in an aeroplane			
Be able to call for a taxi			
<b>Notes:</b>			

Sometimes the challenging behaviours of your PwD aren't caused by the dementia but rather by a break down in the ability of the PwD to communicate their preferences. Take a moment to jot down the things that PwD likes and dislikes. The next time he or she begins to react in a challenging way take a moment to survey the situation and see if anything in the right hand column is present, aggravating the PwD. You may find removing the aggravating object will help to calm down the PwD. We are going to into greater detail about how to identify and react to challenging behaviours later on in the toolkit. The purpose of this section is to get you to start thinking about the PwD beyond their condition.

Things the PwD likes or enjoys...	Things the PwD dislikes

Now that you have completed the profile of the PwD, it's time for you to think about yourself. Use the space below to write a personal profile for yourself. It's important to remember that you are a person first and carer second. Caring can be tough and it takes an admirable person to take on this role, but remember it does not define you as an individual.

### Carer Demographics:

My name is: \_\_\_\_\_

My age is: \_\_\_\_\_

My employment history: \_\_\_\_\_

I was born in: \_\_\_\_\_

If born outside the UK, I have been here \_\_\_\_\_ years.

I became a carer because \_\_\_\_\_

I am in good health: Yes / No

If No: I do have my own health concerns such as:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

The things that I value most in the world are (these can be people, items, personal qualities, etc.):

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

Just like the person you care for, you have likes and dislikes. What are they? Try to make these outside of or unrelated to your caring role if you can.

Things I like or enjoy...	Things I dislike...



# Caring Crisis and How to React

“When he behaves badly I find myself yelling and shouting. It’s not my fault and I guess it’s not him – it’s the circumstance”

Dementia is often accompanied by challenging behaviours (CB) which can lead to a crisis because carers may not always be prepared to handle them. Challenging behaviour is a catch-all term that includes one or combinations of shouting, wandering, biting, throwing objects, repetitive talking, destroying personal possessions and other objects, agitation and general anger, physical attacks on others, and waking others at night. Essentially this describes any behaviour by the PwD that is deemed to be dangerous to themselves, family and friends or those involved in providing care and support.

These challenging behaviours can happen for many reasons. For example the PwD may not understand what is happening causing them to react poorly and lash out. They may act in socially inappropriate ways. They may be frustrated because they cannot communicate or perhaps they may not be able to express their emotions. Seeing you, their carer display emotions like frustration and anger can also affect them.

As a carer, when dealing with challenging behaviours it is important to remember that the PwD is not deliberately being difficult. The PwD’s reality has been altered, and is now different from your own. As a carer you can employ strategies to better manage challenging behaviours, alter how you communicate with the PwD and make small changes to the environment you create at home which can have a massive impact.

The majority of people with dementia will develop challenging behaviours at some point. Common challenging behaviours can include:

- Swearing
- Repetition
- Paranoia
- Hoarding
- Undressing
- Pacing
- Anger and agitation
- Physical aggression
- Verbal aggression
- Inappropriate sexual behaviour
- Obsessive-compulsive behaviours
- Wandering

As a carer, in a time of crisis you may find yourself not knowing what to do, or how to react. Before we go any further, take a minute and in the space below jot down crisis scenarios or challenging behaviours that you have experienced, or fear experiencing. Do you know what to do, or how to react if and when the specific crisis occurs?

On the next page is a table outlining possible triggers for challenging behaviours and related crises; this list is not exhaustive and it is important to remember that each PwD is unique and there is no clear cut guide to dealing with challenging behaviours.

Cause of challenging behaviour	Trigger of challenging behaviour
Medical reasons	Problems with aids such as glasses or hearing aids Discomfort Pain Constipation Infection Depression Dehydration or malnutrition Illness Fatigue Unwanted side effects of medication
Emotional disruptions	Remembering an unpleasant incident Feeling fear or being scared of someone or something Missing someone close to them
Communication failure	Unable to say what they want Unable to explain something Unable to understand others Feeling insulted Feeling frustrated
Environmental overstimulation	Cluttered environment with foreign or unrecognisable items Feeling trapped or claustrophobic Not knowing where he or she is Not knowing where the toilet is Too much noise Too light or too dark Unfamiliar people
Task-oriented activities	Activity is too complex Activity is boring or unsuited to the person’s capabilities Activity is unfamiliar Instructions are overwhelming or confusing PWD lacks coordination required for activity
Response of others	Seeing frustration or anger of other’s at their actions Being rushed by others to work or communicate faster Being taunted by others who point out mistakes, or laugh at the PwD’s errors When someone shows disappointment after the PwD cannot remember or is unable to do something When someone responds to the PwD by crying, shouting, scolding or withdrawing Being ignored by others Seeing others get anxious or agitated

As a carer you are now making decisions that impact not only yourself but the PwD, specifically with how you decide to respond to the PwD when he or she is challenging you, being aggressive or stubborn. Before we get into discussing some practical techniques for managing challenging behaviours, we are going to touch briefly on what it means to make decisions, specifically how you may decide to react to someone who is displaying challenging behaviours.

## Types of Decision Making

Imagine this: you are at home, enjoying a cup of tea in the front room when the PwD rushes in accusing you of stealing a precious item. You calmly tell them you have no idea where the item is. The PwD refuses to acknowledge this and insists that you are lying. Tempers begin to rise and you eventually find yourself shouting at the PwD. You bang your head against the wall with frustration.

Does the above scenario sound familiar? How many times have you felt backed into a corner, frustrated beyond belief and responded in an uncharacteristic way?

For most people, especially carers, you tend to be quite logical in your day to day life. After all you are responsible for maintaining the wellbeing of the PwD, and this requires knowledge, planning and forward thinking. In this scenario however, you made a decision, conscious or otherwise which resulted in reacting to and shouting at the PwD. These actions were driven by emotion versus logic. Emotion driven actions and decisions are very common when caring for a person with dementia.

How we choose to react to a scenario or make a decision is a thought (cognitive) process where the outcome is a choice between alternatives. There are two main types of reactions or decision making processes:

### **Logic based decision making aka “What I should do”**

When a person uses logic to make a decision or react to scenario, he or she will exclude emotions and use only rational methods and tools. The foundation of logical decision making is utility – the value of each option is assessed by assigning a weighted criteria. It is based on factual evidence.

### **Emotions based decision making aka “What I want to do”**

Emotional reactions are driven by opinions and personal interpretations of events. What went through my mind? What disturbed me? What is it that is making me feel this way? What’s the worst thing about that, or the worst thing that could happen? What do I want to do or to happen? What am I feeling? A totally emotional decision is made very fast, often taking less than a second. This is because the area of the brain involved in logic takes time to get warmed up and going, whereas the emotional part of the brain is always switched on and ready to go. This type of decision is reactive and often subconscious. It is the type of decision making you commonly encounter in heated arguments.

In the situation above, although you know that you didn’t steal the item and that the PwD’s reaction is the dementia, not the person speaking, emotions got the better of you and you reacted. In stressful or emotionally charged scenarios it is easy to get wrapped up in the moment and you may decide to react emotionally, which when caring for someone who lacks the ability to have cognitive functions and understand reason, is unhelpful and often causes significant distress both for yourself and the PwD.

When anyone experiences stress it can be difficult to not resort to emotions, especially if you are a carer because there are so many other factors that need to be taken into account, such as the needs of the PwD.

Everybody has the capacity to react both logically and emotionally to stressful situations. As a carer it is important to take both into account in order to come up with balanced responses to these situations. This can be challenging to do, but by doing so it will help to minimise the amount of stress you experience when managing not only the behaviours of the PwD but also when making decisions on their behalf.

Thinking of your caring experiences, describe three different scenarios; one where you’ve reacted to the PwD emotionally, one where you have reacted logically and one where you had a balanced reaction. How was the conflict resolved, how did you feel following the outcome of the scenario? If you need help, think of the example used above where the PwD accused you of stealing; the decision to react in that manner very emotional. What do you think would have happened had the carer reacted logically or had the carer been able to respond to the PwD’s accusations in a balanced way?



## Coping with Challenging Behaviours

It is totally normal to get upset or frustrated when the PwD behaves in an unusual way. As a carer of a PwD it is important to remember that the brain of the PwD has been damaged. This affects what the person can do including their abilities to think, react and remember. It is essential that you try to remain calm and positive, and to practise patience. It is the disease and not the PwD causing these things to occur. Try to let things go and avoid holding grudges over something they do not have control over.

Below are two approaches that you may find useful for dealing with difficult behaviours:

### What, When Where, Why and How Technique

This technique involves you looking at the challenging behaviour from a top down perspective and identify patterns or common themes which contribute to the challenging behaviour.

A. **WHAT:** Identify potential causes of the challenging behaviour by:

Examining the challenging behaviour objectively, take out emotion and use your logical mind. Are the PwD's actions actually a behaviour problem that can lead to a poor outcome or harm for the PwD or others?

Yes, some of the behaviours of the PwD can be embarrassing, disruptive or uncomfortable to be around, but will not be harmful. Avoid correcting, intervening or unintentionally escalating situations. Instead, let it go as long as it is not harming yourself or the PwD. For example, if the PwD would like to wear 4 pairs of socks, let him or her. Protect the PwD from harm and allow for some sense of freedom and control by creating a safe space for them to make their own choices when possible. In the event the behaviour is harmful, try to remove the stimuli or to distract the PwD. If you are in harm's way, remove yourself first. You cannot continue to care for the PwD if you are in hospital, or injured. You need to take care of yourself so you can continue to take care of them.

B. **WHEN:** Look for patterns that help you to predict and prevent problem behaviours by asking yourself the following:

What happened just before the challenging behaviour started? Was there a trigger?

Is there a certain time of day that seems to be more difficult for the PwD?

Are certain times of the year more difficult? For example, in winter when the days are darker and the nights longer.

Remember it is important to recognise, whilst you can predict, you cannot always prevent. Be kind to yourself. Caring for a PwD is a steep learning curve.

C. **WHERE:** To what extent are environmental changes impacting the PwD?

What did it look, sound or smell like? What did the PwD see?

Were there new or different environmental stimuli introduced? New noises, people or places?

Does changing their environment or atmosphere help to soothe or comfort them?

D. **WHY:** Identify the causes of the challenging behaviours

Remember to focus on the why – seek to understand why the PwD is behaving in that way, versus what they are actually doing. For example for a person who is constantly undressing - might their clothes be itchy, tight or uncomfortable?

challenging behaviours are often a reaction to stress or frustrations related to communication difficulties. If you can establish why they are agitated, or what is triggering their discomfort you may be able to use this information to resolve the problem faster.

Put yourself in the PwD's shoes. Look at their body language and imagine what might be triggering this and what he or she may be thinking and what they might be feeling or trying to express.

Does the PwD have an unmet need? Could they be hungry, thirsty, in pain or need to use the toilet?

E. **HOW:** Once you have identified a challenging behaviour, how are you going to react to it?

Validate the feelings of the PwD - if a PwD is upset, their ability to reason may be diminished and the more you try to explain things to them, the more agitated they become. Instead, let the PwD know that you understand they are upset and that you want to help them.

The PwD will respond to your body language, facial expressions and tones of voice. Make sure you use eye contact, smile and if appropriate reassuring touch to help communicate and show compassion. Try your best to maintain your sense of calm.

Be accepting – instead of arguing or correcting the PwD when you disagree. Look for opportunities to validate and accept if possible. For example if the PwD is insisting that they want a cup of tea when you have already made them one they did not drink, instead of saying “no” try “OK, why don't we wait a few minutes and then we can fill the kettle together and wait for the water to boil. In the meantime what do you want to do?” This will validate the PwD and by asking what they want to do in the meantime, distract them and get them to focus on something else.

Introduce a pleasant and calming stimulus – this could be music, a drink, food, pictures, smell, cuddly toy or other items the PwD may enjoy.

Distract and engage them in a favourite hobby or interest, or try looking at photographs of familiar places and faces.

Provide the space for a cooling off period. If safe to do so, give the PwD a bit of space or breathing room to calm themselves down.

### ABC Analysis

Sometimes the PwD may be acting out, yet you see nothing wrong or unusual in the environment or with the situation. ABC analysis can help you to identify triggers of the behaviours so that you can see what needs to be done to reduce the challenging behaviours. This approach is useful for helping you to understand and address challenging behaviours.

It looks at three elements of the scenario in which the challenging behaviours exist.

**A: Antecedent:** The event that happened just before the person got upset.

**B: Behaviour:** The challenging behaviour displayed by the person.

**C: Consequence:** The events happening as a consequence of the behaviour.

This approach encourages you to examine the situation from the perspective of the PwD by taking into account:

**Personal history and characteristics:** Each person has likes, dislikes, fears, habits, etc. Many people find themselves becoming agitated or hurt because of their memories of unpleasant or uncomfortable experiences. When the PwD is acting out, try looking at it from their viewpoint to determine what is causing their challenging behaviours. You as an unpaid carer is well placed to carry out this type of analysis because you generally know the PwD's past.

**The situation as viewed by the person:** The reactions of a PwD are affected by their cognitive functioning; something that was ok earlier may now cause agitation because the PwD's ability to handle it may have declined, or he/she is unable to hide agitation anymore. As a carer it is useful to mentally review the symptoms of dementia that are most commonly experienced to spot possible causes of challenging behaviours.

Observation and creative thinking are great tools to help you discover possible causes of challenging behaviours. As a carer if you choose to use ABC analysis it is important to take into account the following:

1. When examining the situation, look at multiple elements instead of fixating on just one or two potential causes of challenging behaviours. This includes looking at the environment, the tasks being done, interactions with others and communication. For example, a PwD becomes agitated at a family gathering and insists on leaving. What are the possible reasons behind this? Perhaps the PwD cannot follow the conversation, or cannot remember where the bathroom is and is embarrassed to ask.
2. Remember to check for medical conditions such as dehydration, constipation, pain or infection. A PwD may be unable to communicate that he/she is in pain. Some medications cause hallucinations and/or delusions. The time of day is also important; does the person become fatigued in the afternoons, or is hard to wake in the morning due to medications? Aids for sight and hearing may not work properly and this can cause the PwD to become agitated.

Once you are aware of the triggers of challenging behaviours or crisis scenarios you can reduce or remove them; you can also try to reduce the harmful outcome or effect. Just keep checking whether your strategies, solutions and changes are working and readjust as needed.

Now, take a moment, and thinking of the person you care for complete the table below. This exercise aims to help you identify existing and potential crises related to challenging behaviours and come up with a plan of how to react. That way, if and when they happen, you will know what to do. This will greatly decrease your anxiety and give you back a bit of control over the situation. Refer to section B, in particular pay attention to what you wrote down for their likes and dislikes. Use a pencil if you can because you may want to change your responses as time goes by.

									Cause of Challenging Behaviour or Crisis Scenario
									Triggers
									Solution(s) or how I will react
									Outcome (real life, or desired)

## Additional Tools and Tips

A PwD who is agitated can be difficult to deal with because he/she may not understand what is happening. It is difficult for them to control their emotions, and to stay calm. Instead they tend to outwardly display feelings of anger, anxiety, aggression, etc. If they experience hallucinations or delusions, this makes it even more challenging to handle.

Like most people, a PwD can pick up on your emotions and react to them. For example, if you use calm words, but are feeling angry, the PwD will sense your real emotion and will respond to this by becoming more agitated. Things that can help to de-escalate this include:

- Feeling calm (easier said than done we know. Section E will provide you with strategies and coping mechanisms to help with this!)
- Listen and respond to the PwD in a calm, affectionate and reassuring manner
- Use both verbal and non-verbal means of reassurance – for example does the PwD have a sensory impairment such as vision or hearing loss. What can you do to reassure them? Make signs? Gentle touch?
- Avoid arguing- do not insist that the PwD is wrong or being unreasonable
- Try to understand and meet the PwD's emotional need(s)

Your response to the PwD's agitation should be based on their current state, any beliefs they may have and their life history. If the PwD is able to understand explanations, techniques such as reality orientation<sup>1</sup> can be useful. This is more likely in early stages of dementia.

A delusional PwD often may not accept any explanation. Explaining or arguing will agitate them more. In situations like this, try to calm the person without telling them they are wrong. This can be done by first understanding their underlying triggers or emotions and working to address these. There will be times when the trigger is perhaps something you cannot address or remedy. That's ok. You are trying and that's what matters.

For example, the PwD wants to meet a sister who died years ago. The PwD believes the sister is alive and lives next door. The carer says: "Your sister died ten years ago, don't you remember?" The PwD gets very angry, starts shouting and insists the carer is lying. Although the carer in this scenario meant well, their approach was not the best one to take. What do you think could have been said or done instead of challenging the PwD?

As a carer you will need to get creative when it comes to figuring out solutions to challenging behaviours that work for you. In the scenario above instead of challenging the PwD the carer could have:

- Emotionally validated the PwD by asking questions about the sister. This acknowledges the PwD's emotional needs for the sister. The carer could have asked to know about the sister, or said "you really miss her don't you?"
- If the PwD wants the sister to assist with some sort of task or goal, try to find out what that is. Offer your assistance instead.
- Distraction is another option if the emotional needs of the PwD have been met and the PwD is no longer upset.
- Create a soothing environment for the PwD. If they hear soothing music, or smell calming smells this can help to alleviate agitation. In some cases touch and massage can be effective. A fuzzy blanket wrapped around their shoulders for example can help the PwD to feel safe and calm. This is once again completely dependent on the PwD's preferences.

<sup>1</sup> Reality orientation should only be used with mild or early stage dementia. Examples of reality orientation include talking about the present time of day, date and season, using the person's name frequently, discussing current events, asking questions about photos or decorations in the room. In many situations, such as casual daily conversations, reality orientation can be used to help familiarise the PwD to the setting around them.

With the person you care for in mind quickly jot down some sounds, smells, or items that you could easily produce for them during times of agitation.

Sounds	Smells	Personal Items	Types of touch (eg. holding hands)

Now, thinking about the person you take care of, describe below a time when they exhibited challenging behaviour. How did you react to them? What would you do the same and what would you do differently having worked through this section of the toolkit?

Scenario Description	
My Reaction	
Things I would do again	Things I would change



# My Role as Carer

“Caring has taken over my life. I am happy to do so – after all she’s my mum. Sometimes I do find myself feeling guilty because I don’t know if I am doing enough, other times I find myself feeling so angry at the situation and jealous of my friends who don’t have to deal with this...”

Caring for a PwD can be rewarding, but also incredibly demanding. You are going to experience highs and lows related to your caring role that will impact your wellbeing; in addition to the challenges associated with caring for someone with a progressive degenerative disease, such as difficult behaviours (see Section C), you are also going to have to navigate changes to your relationship with the PwD.

Entering into and existing within the caring role can bring to the surface many different emotions which impact on how you interact with and care for the PwD. This section will look into the spectrum of emotions you may feel over the course of your caring role, coping techniques and how to navigate changes to your relationship.

It is important to remember that you are not alone in how you are feeling. There may be days when you feel like you can cope well, and others when you cannot. You have taken on an enormous responsibility caring for a PwD and the emotions you experience are completely normal and justified.

## Emotional Impact of Caring for a PwD

One of the most difficult things about caring for a PwD is the spectrum of emotions you’ll experience. You may find yourself feeling frustrated, stressed or depressed. You may be angry and wonder “why me?” You may also feel guilty for thinking about yourself instead of the person you care for or even experience a sense of loss. Feeling these emotions is a very common reaction to caring for a PwD. Don’t be ashamed about how you feel as there are other carers experiencing the same. It is important to learn to identify your feelings and how to deal with them effectively so that they do not negatively impact on other areas of your life.

**Anger:** You at times find yourself feeling like you are at your wits’ end or exploding. Experiencing anger and frustration is a normal part of being around someone who requires support on an ongoing basis who may refuse this or challenge you. PwD are often combative and irrational; this makes caring for them even harder. It’s not always possible to control your emotions and sometimes anger will just come out.

**Anxiety:** As a carer you may feel like things are spiralling out of control and you may not know how to regain this, leading to feelings of anxiousness. Anxiety can present itself in many ways; it can emerge as a short fuse, the impulse to run away, sleeplessness, heart palpitations or the urge to cry.

**Frustration:** Sometimes, as a carer, you may experience situations where you feel that you can’t do anything right or that things just don’t go as planned no matter what you do or how hard you try. And if you are tired, you are more likely to get frustrated. Frustration may lead to stress eating, negative coping behaviours such as drinking alcohol or smoking and increase the chances of you losing your temper.

**Stress:** Stress is part of everyday life. It is caused by the many demands made on time, energy and the expectations you may hold for yourself. Not all stress is negative, sometimes stress can alert you to potential dangers and can also spur you on to achieve a goal or complete a task. For carers, sometimes the balance tips too far and the pressure becomes so intense or so persistent that you may feel unable to cope, and this in turn affects your health and wellbeing.

**Depression and/or low mood:** One in five people will experience some form of depression. Usually this will present as a temporary low accompanied by feeling hopeless or helpless, the inability to sleep, or trouble getting up and facing the day, with things gradually improving until you feel back to your normal self. As a carer, you are at risk of depression as a result of your caring role.

**Embarrassment:** Does the PwD sometimes make inappropriate or rude comments when you are out in public? Does he or she dress inappropriately for the weather? Does he or she refuse to bathe and now has body odour? As a carer it’s often easy to feel responsible for the behaviour of someone else and feel like it is your fault when these things happen.

**Fear:** What if something happens to the PwD? Will I be able to cope if their care needs increase? Am I responsible for things that go wrong? Carers of PwD take on a huge amount of responsibility, not only for the day to day care, but also for all the other things that “might” happen. The “what ifs” can be scary and can keep you from enjoying the time that you have with the PwD.

**Impatience:** Do you struggle to get the PwD up and ready in the morning, make sure that he or she has breakfast, is dressed and arrives at a hospital appointment on time? Does the PwD act in unhelpful ways and is slow moving? Do you have other things to accomplish during the day which now are impossible due to time constraints? Perhaps the PwD refuses to use the zimmer frame even though he/she has fallen many times and you have emphasized he/she always needs to use it. It is understandable that you would get impatient at times.

**Loneliness:** Many carers of PwD report feeling isolated and lonely as a result of their caring role. As the dementia progresses you may find the PwD less willing to leave the house. You in turn must stay in with them in case he/she requires something. Eventually you may find yourself going days without speaking to anyone but the PwD, it is easy to lose a sense of yourself. Friends stop calling since you’ve cancelled plans so many times and you hesitate to call them because you don’t want to burden them with your problems.

**Resentment:** Becoming a carer is something that cannot always be foreseen. When put in a situation not of our choosing, it’s not uncommon to feel negative and resentful. Perhaps you have siblings who are not helping provide care or maybe you are an only child, became the carer by default, when you have very little desire to offer care. Little things easily become big things when we feel unappreciated and unacknowledged - and feeling like you have to do it all, and do it all by yourself, is a sure fire way to build resentment.

**Jealousy:** Do you ever feel jealous of your friends or family members who are able to go out and do things that you can no longer do, because of your caring responsibilities? It is often difficult to admit to this feeling, because societally we have always been told not to be jealous. But that doesn’t mean that from time to time we don’t feel jealous of those who have it easier or better than us.

**Overwhelmed:** Caring for a PwD comes with loads of responsibility and worry – feeling overwhelmed by this is totally natural. Feeling overwhelmed is often a combination of feeling emotionally and physically exhausted, underappreciated and apprehensive of the amount of work that needs to be done.

**Grief and loss:** Watching the PwD decline, not being able to do things that used to be easy and natural, is sad. We also grieve for the PwD, the person who used to be and our relationship with that person. We often need to grieve the loss we are experiencing on a daily basis or it will come out as something else. There is also grief related to your loss of self, and the person that you used to be prior to taking on your caring role.

**Guilt:** This is a very common feeling to experience when caring for a PwD. As a carer you have taken on a very important, high stress job. Guilt can present itself in many forms:

- There is guilt over not having done enough to have prevented them from getting ill in the first place.
- There is guilt over feeling like you want this to end.
- Or guilt over having been impatient with your PwD as their symptoms were developing.
- There is guilt over not loving or even liking the PwD at times.
- There is guilt over not doing enough for the PwD or not doing a “good enough job” as a carer.

Most commonly, carers often find themselves feeling guilty for thinking of their own needs and see themselves as selfish, especially if they should do something that doesn’t include the PwD like go to the cinema or out for a meal with friends. Experiencing physical or emotional exhaustion due to one or a combination of the above is commonly referred to as caregiver strain or caregiver burden. It is important to develop effective coping strategies that work for you and to establish a support network of individuals (Section E) who may be able to help you with your caring duties. We suggest that you keep a journal to document how you are feeling during particularly challenging times.

Complete the exercise below. Mark off the emotions in the table and how often you feel them. If you find yourself ticking “most of the time” or “some of the time” how do you normally cope with these feelings? Write down your strategies for coping in the space provided.

## Coping Techniques

I feel angry...	Most of the time <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Rarely or never <input type="checkbox"/>
Some things I already do which help me cope include...			
Suggested coping techniques	<p>First off forgive yourself! It's okay to get angry. You find this difficult to do, but keep on it. Forgiveness comes with time</p> <p>Walk away and give yourself some time out.</p> <p>Identify a support network of people who are empathetic and you can vent to. If you can't think of anyone, listening ear services such as the one at the carers centre.</p>		

I feel anxious...	Most of the time <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Rarely or never <input type="checkbox"/>
Some things I already do which help me cope include...			
Suggested coping techniques	<p>Pay attention to your anxiety- this is your body giving you a warning that something is not right</p> <p>When you feel anxious – STOP even if it's just for a few seconds. Pay attention to your breathing and slow it by taking a few deep breaths. Then do something that will give you a break from the physical and psychological symptoms such as praying, meditating, making a cup of tea. Participating in little rituals are a great way to give yourself the space to manage the anxiety.</p>		

I feel frustrated...	Most of the time <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Rarely or never <input type="checkbox"/>
Some things I already do which help me cope include...			
Suggested coping techniques	<p>Be honest with yourself - acknowledge that your role as a carer is frustrating at times.</p> <p>Give yourself a break from the PwD – be it going on a short break, walking into the other room or simply putting on some headphones and listening to some music for a few minutes.</p> <p>Disengage yourself from the situation that is frustrating you. If the person follows you into the room, try some of the exercises listed in Section F to give yourself the mental space away from the PwD.</p> <p>Meet other carers who are in similar situations and share tricks, vent if you need it. Remember though, they may also want to vent, and it is important to protect yourself. If you do not feel you have the capacity to take on other's experiences it's ok to take a step back.</p>		

I feel stressed out...	Most of the time <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Rarely or never <input type="checkbox"/>
Some things I already do which help me cope include...			
Suggested coping techniques	<p>Identify your triggers or what makes you feel stressed. Noting down when you feel stressed and why in a diary or in the notes pages of this toolkit can be helpful.</p> <p>Write down your symptoms of stress (both physical and psychological).</p> <p>Looking at 1 and 2 above, come up with a plan for what to do when you notice triggers of stress. This can include meditation, going for a walk, breathing exercises, anything that helps to calm you down. Write this in your diary so you can refer back to it if needed.</p> <p>See what you can change about the stress-causing situations and accept what you cannot change.</p> <p>Ask for help when you need it. Do not go at it alone. Speak to someone! It could be your GP, the social worker of the PwD, support workers or the City and Hackney Carers Centre. Services exist to support you. If you are unsure of where to find them - ask.</p> <p>Seek out additional support such as counselling. If feel you can't get out of the house, or are not ready to speak to a psychologist or psychotherapist there are now online psycho-education programmes you can access to learn tricks to deal with stress. Check out section F for a free service in Hackney and the City.</p>		

I feel low/ depressed...	Most of the time <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Rarely or never <input type="checkbox"/>
Some things I already do which help me cope include...			
Suggested coping techniques	<p>Acknowledge it, depression is treatable.</p> <p>Seek out professional help from your GP.</p> <p>Write down how you're feeling, join a carer support group or seek out counselling in person or online. Acknowledging your feelings and putting them out there can be a massive relief.</p> <p>Exercise, getting your body moving is a proven way to relieve some symptoms of depression.</p>		

I feel embarrassed	Most of the time <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Rarely or never <input type="checkbox"/>
Some things I already do which help me cope include...			
Suggested coping techniques	<p>Understand that the behaviours are a result of the disease and can't be controlled by the PwD.</p> <p>Try creating little cards which read "my _____ (partner/father/mother, etc.) has dementia and sometimes can't control their behaviour". You can hand these out to those around you.</p>		

I feel scared/ fearful...	Most of the time <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Rarely or never <input type="checkbox"/>
Some things I already do which help me cope include...			
Suggested coping techniques	<p>It is important to have a backup plan in case something does go awry. Write this down somewhere and ensure a family member or friend knows where to find it.</p> <p>Get a Carers Emergency Card and keep this in your wallet or purse</p> <p>Talk to someone (counsellor, GP, friend, family member).</p>		

I feel impatient...	Most of the time <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Rarely or never <input type="checkbox"/>
Some things I already do which help me cope include...			
Suggested coping techniques	<p><b>SLOW DOWN.</b></p> <p>Leave additional time to complete tasks.</p> <p>Control the environment as much as you can. Create a list of things you can and cannot control. Accept the things you cannot control.</p>		

I feel lonely...	Most of the time <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Rarely or never <input type="checkbox"/>
Some things I already do which help me cope include...			
Suggested coping techniques	<p>Find ways to get out of the house, bring the PwD with you if you need to.</p> <p>Have a hobby that is something other than caregiving.</p> <p>Join online communities with other carers of PwD who just understand what you're going through.</p> <p>Contact local community agencies who may be able to signpost or refer you into services/ programmes. Befriending and other support services exist; they can act as a buffer between you and the PwD. They can offer a listening ear and offload some burden.</p>		

I feel resentful...	Most of the time <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Rarely or never <input type="checkbox"/>
Some things I already do which help me cope include...			
Suggested coping techniques	<p>Family dynamics can be complicated. Getting help from your family can make the caring role easier but sometimes family tensions make it difficult to reach out. If family tensions are getting in the way, refer to Dementia: How to Avoid Conflict booklet.</p> <p>Consider broadening your circle of people to include others that can and are willing to help.</p>		

I feel jealous...	Most of the time <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Rarely or never <input type="checkbox"/>
Some things I already do which help me cope include...			
Suggested coping techniques	<p>Remember it's okay to be jealous from time to time. Jealousy is only a problem when you become enveloped by it.</p> <p>Focus on what you do have, whatever it may be, regardless how small.</p> <p>Find a place within you for gratitude towards what you do have.</p>		

I feel overwhelmed	Most of the time <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Rarely or never <input type="checkbox"/>
Some things I already do which help me cope include...			
Suggested coping techniques	<p>Develop manageable routines. It's okay to take your time and to not complete tasks immediately.</p> <p>Concentrate on the PwD's existing abilities and set reasonable targets. This goes for you as a carer too, what can you manage realistically.</p> <p>Feeling stressed and overwhelmed is understandable, talk to someone about how you are feeling.</p>		

I feel grief or loss...	Most of the time <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Rarely or never <input type="checkbox"/>
Some things I already do which help me cope include...			
Suggested coping techniques	<p>Try creating a ritual as a way to say goodbye such as writing a thing down that the PwD can no longer do on a stone and throwing it into the canal, or putting it into a box. It is important to allow yourself to feel pain and sadness to promote your own healing.</p> <p>Identify and accept your feelings. Prepare to feel these more than once over your caregiving journey.</p> <p>Relieve tension by crying, or punching a pillow.</p> <p>Care for yourself – do something fun, get some exercise, treat yourself regularly and talk to someone.</p>		

I feel guilty...	Most of the time <input type="checkbox"/>	Some of the time <input type="checkbox"/>	Rarely or never <input type="checkbox"/>
Some things I already do which help me cope include...			
Suggested coping techniques	<p>Know your limits - be realistic about your capabilities. No one is perfect, set yourself up by setting achievable caring goals.</p> <p>Learn to prioritise – work out which things you really need to do versus things that would be nice to do.</p> <p>Don't compare yourself, or your situation, to other carers.</p> <p>Confront your feelings – understand why you are feeling the way you are. Being aware of your negative feelings makes it easier to move on.</p> <p>Give yourself permission to forgive yourself. No one is perfect. Try keeping a journal; this can be a safe non-judgemental place for you to express your feelings.</p>		

## Changes to Your Relationship with the PwD

As you enter into your caring role, you may notice that your relationship with the PwD changes and that you must adapt to the demands of caring. As a result of this you may find yourself experiencing feelings of confusion regarding the shift in dynamics and the changes to, or in some cases the loss of, your relationship.

### Caring for a Partner

As the disease progresses, your relationship with your partner will change; you will find yourself taking on a new role in your relationship as your partner's memory declines. In many instances the PwD may no longer be able to perform certain tasks such as household chores, managing finances or legal matters. As both a carer and partner, be prepared for these changes. It is important to discuss with the PwD the location of important documents, power of attorney and other legal matters. Add both your names to any financial accounts that were previously just in his or her name.

Grief is a common reaction to the changes in your relationship. It is important to remember that this is normal, and you are not self-centred or callous. As your partner's cognitive abilities decline you will no longer be able to have the same physical and emotional connection that you once shared.

With regards to sexual relationships, people with dementia diagnoses, are just like other people, they have sexual needs. Sexuality contributes to a person's sense of who he or she is, and when engaged with can help people to hold onto a sense of their own identity. Further, being sexual in a relationship is part of how individuals have a sense of closeness and intimacy with their partner. As a carer the potential loss of the sexual relationship with your partner is a major part of the grief and sense of loss that you may be experiencing. If you are tired and exhausted, frustrated and confused, it is difficult to feel sexually attractive. For the PwD, changes in libido (either depressed or enhanced) are common and dependent on which parts of the brain have been damaged and which medications have been prescribed.

For some couples, they have experienced minimal disruptions to their sexual relationship whilst others have discovered new ways that work for them. Each couple is unique; therefore try not to compare your situation to others. It's important for you to take into account your history of being a couple, including how you have resolved problems within the relationship and how intimacy was expressed in the past. These will affect how you are able to cope within the current circumstances. You may choose to think outside the box and explore other ways to express intimacy and ways to enjoy nonverbal expressions of closeness. Acknowledging that your relationship has changed, and to mourn any loss that is felt is important.

For you, as a carer, there is also the added dilemma of wondering or feeling like you may be taking advantage of your partner when initiating sex; specifically when it may be difficult to determine if the act is consensual. In some circumstances, the PwD will be very responsive to sexual advances and be able to verbalise this. In other circumstances he or she may passively accept sexual advances. This can often be confusing for you as their partner; if he or she is unable to verbalise their willingness to engage in a sexual act it is key to learn how to identify the non-verbal signs of non-consent and stop. It is also important to take into account how you feel engaging in an intimate relationship with a PwD, and be aware of your willingness to consent to engage in sexual activity. Sometimes the PwD may not be aware of your reluctance and could respond in an insensitive manner. In these instances you will need to show that you do not consent.

It may be difficult at first for you to accept these changes, and you may find yourself struggling to cope with the change in role from partner to carer. If you are caring for your partner there are 5 key things you can do to help make the transition a little bit easier.

- 1. Accept the diagnosis** – Your partner has been diagnosed with a progressive disease for which there is no cure. You are likely going to experience a range of emotions from guilt and loss to anger and resentment. By accepting the diagnosis early on you can learn to better understand the disease as well as techniques and strategies that can be employed to effectively care for the PwD. Preparing in such a way will help you to better manage difficult situations and challenging behaviours, thus decreasing your own stress.
- 2. Include the PwD in decision making** – Involve your partner as much as you can in making decisions that directly impact them such as shopping for personal items, deciding on daily activities, medical procedures etc. Ensure that for higher risk activities such as cooking or driving the PwD is supervised as the disease causes impaired judgement and communication.
- 3. Create a daily routine** – Set up a balanced routine for yourself and your partner. Include light physical activities such as walking or exercising. For both of you it is important to maintain regular contact with friends and family. Assess the environments in which the PwD is most comfortable to reduce anxiety and agitation. The PwD may struggle in crowded places; if this is the case perhaps opt to meet at home or at a quiet café near your home. You may find yourself wanting to coddle your partner, it is important that you promote him/her to maintain independence. This can be achieved by encouraging your partner to engage in housework, outings and hobbies that they enjoy.

4. **Set up a support system for you** - Caring for a partner with dementia can be scary, and it is important early on to identify your limits and decide how you want to be involved in caring for your partner. Do you need help from paid carers? What type of support do you need from family members, children and friends? Take your own health into account when setting up support – can you physically and emotionally handle the requisites of caring for a PwD? Most people find caring for a partner with dementia to be rewarding, but it does come with its challenges. You may find yourself exhausted, depressed or isolated. Remember that it is okay for you to need support too. You can only care for your partner if you are well. Find a support group; seek out counselling or online mental health services.
5. **Look after yourself** – Leading on from point 4, caring for someone when you are healthy is challenging, doing it when you are unwell makes it feel nearly impossible. The caring role will become more difficult if you don't feel in good shape psychologically, emotionally or physically. You may sometimes feel as though things are spiralling out of control. Try to learn simple ways to calm both your body and mind. Regular periods of rest and relaxation are essential. Meditation, deep breathing and positive affirmations are proven to be effective. There are lots of free apps that can help you get started. Part F goes into greater detail about this.

Your relationship with your partner will undoubtedly change as a result of the dementia. However your connection can still be rich and fulfilling. Spend time together in ways that bring you closer and help you relate, have open dialogue about both your feelings and seek help if you feel you need it.

### **Caring for a Parent**

Witnessing a parent develop dementia is one of the hardest things a person can face as an adult. You see the person who raised you and protected you become more dependent and increasingly disabled over a long period of time. It brings to light their vulnerabilities which for you can be scary as they were once your authority figure and dominant power holder in your relationship. When it comes to parents, most adult children are usually very sensible and approach providing care from a pragmatic point of view. That being said, caring for a parent takes a lot of patience and flexibility, and you as an adult child may have additional things that need to be taken into consideration when caring for the PwD such as young children, your living situation, financial status and employment.

Although it can be hard to look after a parent with dementia, there are things you can do to help ease the frustration and increase your patience while caring for them.

1. **Scheduling** – Establishing a routine for your parent's day to day life will help to make things more predictable, stable and less stressful. Try to arrange appointments for times of the day when your parent is calmer and more agreeable. If you don't live with you parent, creating a routine where you visit them before and after work helps to ensure that they stay safe.
2. **Cues** – if you can afford it, you can purchase dementia specific homewares and appliances which help to remove potential dangers. If the PwD is agreeable, label drawers and cupboards so the PwD is able to put things away correctly and independently.
3. **Determine the level of care that both of you can afford** - assess your financial options for caring for your parents. Do they have enough resources to pay for in-home caregivers or to move into a care home or retirement village that provides medications and basic daily supervision? You may want to open up your home and have your parent live with you. How will you manage both the financial and practical implications of this?
4. **Be present with them** – this includes both physically and emotionally present. By spending regular intervals of time with the PwD you can check in to see how they are coping, and whether or not they are declining. Furthermore spending quality time with a PwD can improve their quality of life and decrease isolation which has been linked to cognitive decline.
5. **Integrate your parent into some choice activities** – this creates the space for you to maintain your relationship with your parent. This could be as simple as taking them grocery shopping, or a trip to the library. Involving your parent in the decision making helps to empower him/her and provide stimulation.

### **Caring for a Friend**

Making and maintaining friendships are important for most people. This need does not diminish following a dementia diagnosis. In fact, it's likely that during this difficult transition, the PwD will need their friends the most. It is common that a lack of knowledge surrounding dementia, or fear of the unknown, can negatively interfere with a person's ability to carry on a friendship. Although changes such as cognition and communication abilities will occur as a result of the dementia, it is important to remember that the core elements of the friendship remain.

If you are helping to care for a friend, in addition to the tips listed in the "Caring for a Parent" section it is important to take the following into account:

- Be prepared to 'walk a mile in their shoes' and imagine the impact that the dementia is having on your friend. This can help for you to learn to accept the changes that are happening.
- Don't take mistakes personally. Mix ups of names and memories are common.
- The PwD may lash out at you because they are feeling confused, bereaved or even angry at what is happening to them.
- Let your friendship remain a relaxed relationship without the emotional overtones of family interactions (if family members are also involved in caring for the PwD).
- Remind yourself that what a person needs at this time is a really good friend.
- If family members are the primary carers, when possible be a friendly visitor to them and offer to take over to give the family member a bit of respite.





# Who Can Help Me Help Them?

At some point during your journey as a carer you will need help from others and it can come in a variety of forms. You may need someone to come and sit with the PwD whilst you attend a doctor's appointment, you may need some extra assistance keeping on top of housework or you may simply want someone to talk to after a hard day. It is important that you identify individuals in your family, community or support network who you can call on during times of need for support. Take a moment to think of all the people in your life who are important to you, make sure to write down their names in the space below.

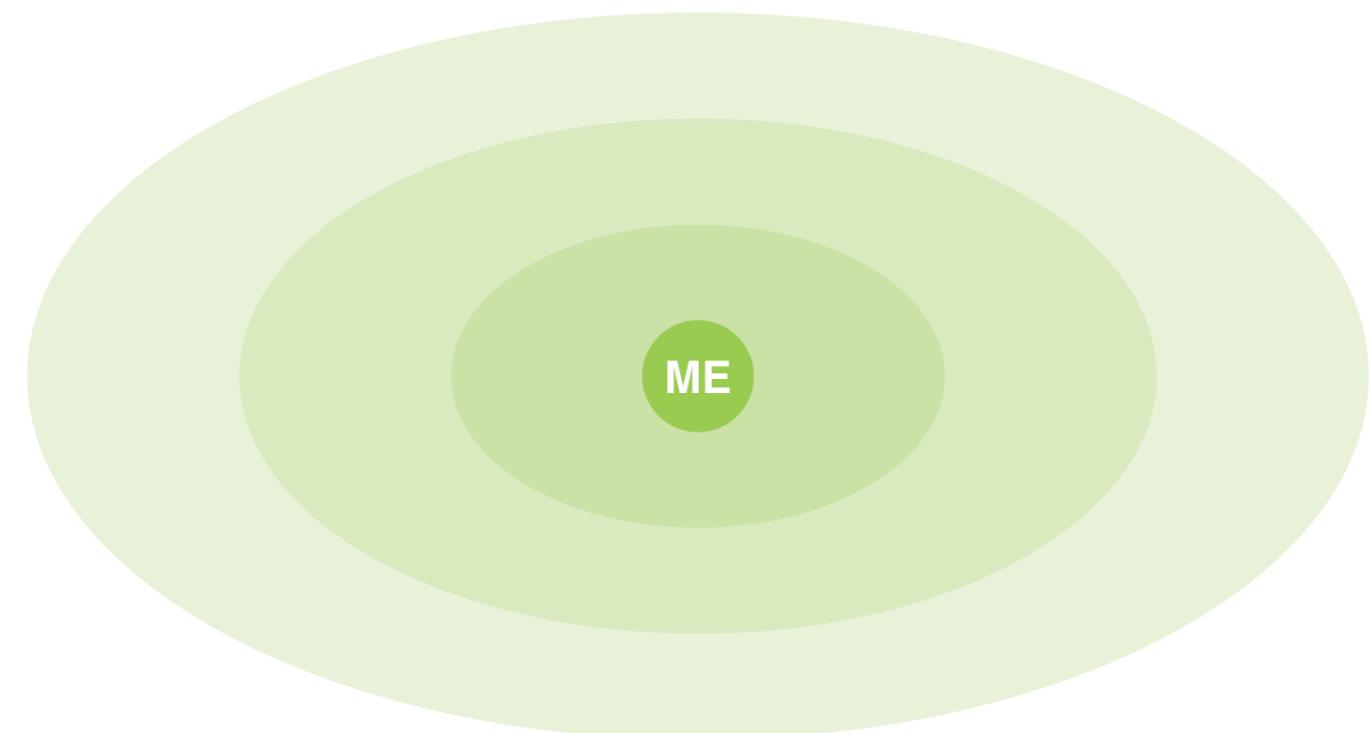
People that are important to me:

Now complete the following exercise: Carer Closeness Circle Exercise

Here we have a series of circles one within another with the word "ME" in the centre. Take that list of important people and place them in these circles. The people in the circles closest to "ME" are those that you feel the closest or most connected to (even if sometimes it's not all positive). These relationships are considered to be loving relationships; people within this circle may be family members, children, close friends. People in the circles further away from the "ME" are people who are important to you but you may not feel as close to them. They may be members of your wider social network, aunts, uncles or cousins. A good way to determine who falls within this circle and who falls within the first is to ask yourself the following questions:

- Who do I call when I've got good news?
- Who do I go to moan to if I've had a bad day?
- Who do I share secrets with?
- Who do I share a laugh with?

People in the larger circles, further away from "ME" are people who are important to you but to whom you may not feel as close. They could be neighbours, colleagues, members of your church or other community groups.



Once you have completed the circle think about which of those people may be able to help you with the PwD if needed. List your top five people below along with their contact details, relationship to you and reasons for choosing them.

Name	Contact Number	Relationship to me	Why I chose them

It is also useful to list the health and social care professionals who are involved in your PwD's care. It is important to make it known that you are the PwD's carer and that you need to be involved in conversations pertaining to their care and support needs - after all you know them best!

Professional	Name	Their Role in PWD care	Contact number	Contact email
GP				
Consultant				
Social worker				
District Nurse				
Community Matron				
Dementia Navigator/ Advisor				
Psychologist				
Pharmacist				

## Emergency Planning:

Making sure that you have a plan in the event that you are unable to care for the PwD is essential. An emergency plan should help you to identify the people who are already in your life that that can help with caring. Look at the names you put in your circle; would any of them be willing and able to step up in your absence? You might want to have individual conversations with potential emergency contacts or you could try getting everyone together to talk it through. You will want to tell everyone what your emergency plan is so that they are aware and prepared.

When coming up with your emergency plan you will need to take into account both your needs and those of the PwD. Take 5-10 minutes to think of these and fill in the brief plan below. Remember the aim of the plan is to create an informal network of support around yourself and your cared for. If an emergency arises, you can be feel assured that people you know and trust will step in to your caring role. An emergency plan can prevent an emergency becoming a crisis. Feel free to expand on this and turn it into your formal plan to be shared with relevant individuals. You can even turn it into a message in a bottle plan (<https://carers.org/article/message-bottle>).

Who do I care for? (Describe them using the personal profile you created in Part B)

Who do I want involved in my emergency plan and related discussions? (Friends, family, healthcare professionals)

What care and support does this person need? What is their day to day routine? Who do I know that can help with specific tasks (i.e. grocery shopping, chores, personal care)

*\*It might help to think about an average day – from when you both get up until you go to bed at night.\**

Does the PwD have any other specific needs? (i.e. dietary, communication, etc.)

What are their healthcare needs? Do they take regular medications? If so, where are they kept? Can they take them alone or do they need help?

Who is the PwD's next of kin (aside from me)? Who has Power of Attorney? Who are the main agencies or professionals that need to be contacted?

Is there anything else you can think would be important to include in this plan?

Remember, you are not alone in your caring role. There are many others just like you who care for a PwD with dementia. Local charities and other organisations exist to help you with your role. In Hackney, the City and Hackney Carers Centre and local Alzheimer's Society branch can help you to navigate your role.

As a carer, in line with the Care Act 2014 (<https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/care-act-faq>), you are also entitled to a carers needs assessment which is a statutory assessment exploring the ways in which your caring role impact on your emotional, psychological and physical health and wellbeing. This is a great way to formally document your caring experience and to access additional support and services you may not be aware of. You are entitled to one assessment per calendar year, however If your circumstances change, and you find that you are struggling to cope even more, you can request an emergency assessment. Contact the City and Hackney Carers Centre or, the PwD's Community Care Navigator to find out how to request an assessment.

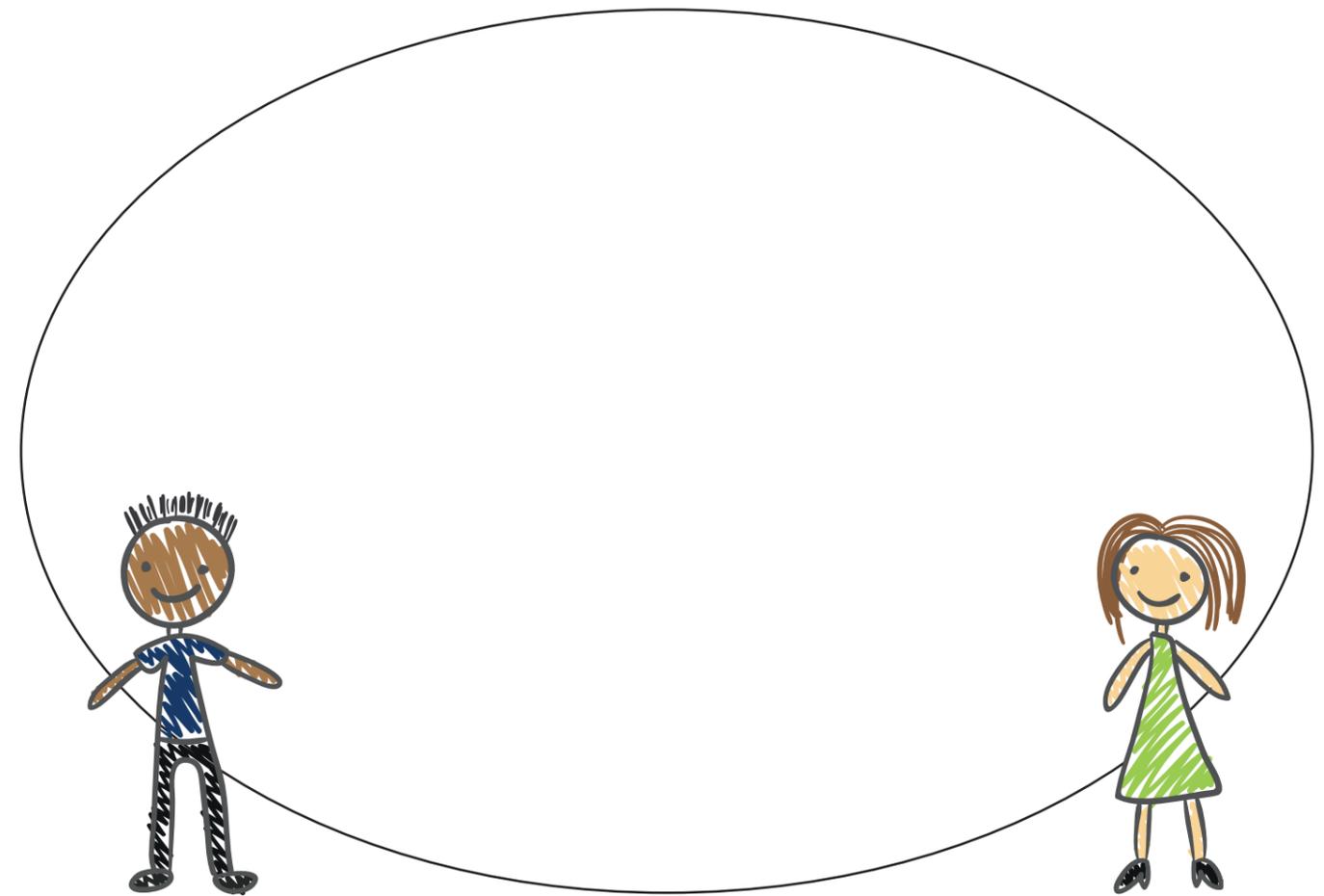


# Self Care for the Carer

You will know more than anyone that caring for a PwD is a challenging role; it's incredibly stressful and it can result in physical, psychological and emotional exhaustion. As a carer you are also probably aware that taking care of yourself — physically and mentally — is one of the most important things you can do. This is, however, easier said than done.

Self-care is the practice of taking action to preserve or improve one's own health. You know that self-care is essential to continue on in your caring role; you should be looking after yourself, taking breaks, addressing your own health needs. It's not a lack of knowledge that is stopping you from engaging in self-care activities, but more likely a lack of time and a long list of caring tasks that you feel simply must be done.

Before we go any further, take a moment and think about what is your definition of self-care? What does it look like to you? Is it the same as the definition above? Or is it different? Think about what you could benefit from including into your day to day life. It could be more breaks, getting more sleep, weekly tea and chat with a friend, or family member. In the space below write down all the things that you would like to make room for in your life.



Now that you have identified what self-care is to you, how many of the self-care activities listed above are you actually making time for? Place a check mark next to activities that you have done in the last week or two. What do you notice? Are the majority of items above checked? Or are they not? Regardless of how many activities or items you have checked off, there is a good chance that you wish you were engaging in or with more.

The reasons that you may not be making enough time for self-care are valid; you are busy, your caring role is unique and your life is full of barriers and obstacles. What is interesting though, in some cases these barriers are actually self-imposed reinforced by what you feel you have to do or the beliefs that you hold. As a carer for a PwD you will come up against so many things that you have no control over, recognising your own barriers to self-care and making changes to overcome these is something that you can control.

This section will help you to identify what your barriers to self-care are and provide some suggestions for quick and easy things that you can do to help integrate self-care into your day to day life.

## Barriers to Self-Care

First of all, what is stopping you? What do you think are the barriers preventing you from taking care of yourself? Take a moment to think about these, be brutally honest, they may be practical reasons (i.e. not having the time) or theoretical (i.e. you feel that you will be judged by others for taking time for you). Now write these down in the space below, try to list as many as you can. If you run out of room continue them on another piece of paper or if you are keeping a journal (as discussed in Part D), write them down in there.

My barriers to self-care are...

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.
- 9.
- 10.



Now that you have identified the barriers that are stopping you from making time for yourself, you can start to think of small changes that you can make. The first thing that you can do is reflect on your list and take note of any negative self-talk or beliefs and challenge these. For example you might have written down: "I am the only person who can get him/her to eat" – is that true? Or can others help you? Where did this belief come from?

Challenge the barriers you have listed above and come up with a counter argument for each, include the source of the belief if you want. Write them in the space below:

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.
- 9.
- 10.



You have identified what self-care looks like to you, barriers and counter arguments. It's now time to think about what your motivations are behind these activities. Without clear motivations in your mind you may find yourself slipping back into old behaviours and not prioritising your needs. In the space below write down the benefits of self-care and what your motivations are for looking after yourself?

Now that you have identified your motivations, it's time to start planning and setting small self-care goals for yourself. A little while ago, we used the example of meeting a friend for a cup of tea and a chat as a form of self-care. What are you going to have to do or what will you need to make this happen? Will you go to theirs and bring the PwD with you? Will they come to you? Will you go out, and if so, are you going to bring the PwD with you, or ask someone to come and sit with them? How much time do you feel you can give yourself? Why did you choose to meet this particular person?

Look at your list of self-care activities that you would like to engage with and identify your top three. In the space below start planning for how you are going to achieve these. Think widely and creatively; and, most importantly of all, think what will work and be manageable for you. This will most likely change over time as the PwD declines and changes to your living, work or personal life occur. It is important to be flexible and to remember to forgive yourself on the days that you might not have been able to take time for yourself.

My top three self-care activities are...

- 1.
- 2.
- 3.

Have you struggled to come up with ideas for self-care activities? Below are some ideas of simple self-care rituals that you can use to help decrease stress, improve both your physical and psychological health and to ultimately cope with the demands of your caring role and avoid burnout.

## Sleep

Finding time to sleep may be one of the biggest challenges faced by carers of PwD, the second being able to relax enough to actually fall asleep. Does this sound like you? Over two-thirds of carers of PwD have problems sleeping. Stress related to your caring role disrupts your sleep, can make you feel low, and affects your overall health. If the PwD is ill, experiences sun-downing (a symptom of dementia where the confusion and agitation gets worse in the late afternoon and evening) or wakes up frequently, it only gets worse. It is important to try to get as close to 7-8 hours of sleep as you can. Sleep deprivation can cause issues focussing, mood swings, weight gain and affect your immune system – all of which are major contributors to stress and caregiver burnout.

Some easy ways that you can improve your sleep include:

1. **Devote your sleeping area to sleep only.** That means no caring related work. Keep it clear of objects or clutter that might remind you of caring, for instance hospital letters or legal paperwork. This is very important if the PwD lives with you. Train your mind to mentally view the physical spaces in your home for sleeping as separate from the ones associated with the stresses of caring. If you worry about the PwD when they are sleeping, get a baby monitor to keep an eye on them, but avoid sleeping in the same room with them.
2. **Reduce Stress at night.** You've had a stressful day caring for the PwD, it is important to not take this to bed with you. Relieve your stress through coming up with a calming routine that you can do before going to bed. It can include relaxing activities such as taking a bath or shower, knitting, reading a book or watching your favourite show. By creating a routine you are conditioning your mind and body to recognise that you are preparing for sleep. Thus making it easier to actually fall asleep. There are also exercises you can do whilst in bed that can help to relieve stress and prepare your body and mind for sleep. Below are a few different exercises you can try.

### Progressive Muscle Relaxation

This is one technique that has been proven to help reduce stress at night. It is a mind-body relaxation technique that helps you to become familiar with your body and the places where you hold stress and tension. You tense and then relax groups of muscles in the body- this creates an awareness of what both tension and relaxation feel like in your body. When incorporated into your nightly routine, progressive relaxation can help you release physical and mental tension that often interferes with sleep.

Here is an example of a typical progressive muscle relaxation sequence you can follow:

Lying on your back with palms facing downwards take a minute to feel the pressure of your mattress on your back, take note of how the sheets feel and the weight of the duvet. What do you hear around you? Take a moment to appreciate the sounds and sensations around you. Take a deep breath in and release.

Tense the muscles and hold for 15 -30 seconds each and then relax for 10-20 seconds before moving onto the next muscle group. The whole exercise should take approximately 5 minutes. Repeat if you still sense stress or tension.

1. Right foot, then left foot
2. Right calf, then left calf
3. Right thigh, then left thigh
4. Hips and buttocks
5. Stomach
6. Chest
7. Back
8. Right arm and hand, then left arm and hand
9. Neck and shoulders
10. Face

### Breathing Exercises

Breathing exercises are also an effective way to combat stress. They can help to calm your nervous system, and prepare these are also an effective way to combat stress. They can help to calm your nervous system, and prepare your body for sleep. Did you know that training your breath is just like any sort of exercise? The more you do it, the better you get at it. With enough practice you will fall asleep faster at night, and eventually you will feel less stressed during the day. Below are some exercises you can try.

#### **Meditative Breath**

Try incorporating a short meditation practice before getting into bed. Sit on the floor, or in a sturdy chair. Keep your back straight and head slightly tucked forward. Start off by breathing normally for three breaths and when you feel ready start to progressively lengthen them.

For the first exhale, count to one. Then count to two, then three, up to five. After your fifth exhale, hold for a count of five, start over again at one. By keeping to this pattern you keep your mind focused on your breath instead of stress or anxiety. Try this for 5 minutes to start and work your way up to 10.

#### **Alternating Nostril Breath**

There's a reason why our breath quickens and we pant when we get excited or nervous. Breathing through your mouth stresses the body, whilst breathing through the nose keeps your body in a steady, more relaxed state. Try tuning into your nasal breathing by using a yoga breathing technique called *nadi shodhana*. Sitting up, with your legs dangling over the side of your bed and bottom firmly placed breathe in through one nostril while you gently block the other one by pressing your finger against it. When you exhale, release your finger and breathe through the other nostril, blocking the opposite nostril. Continue breathing like this for two to five minutes, or until you feel a calm wash over you.

#### **Diaphragmatic Breath**

Lying on your back with one hand resting on your lower stomach and the other on your chest, take five deep breaths, inhaling for a count of three and then exhaling for a count of three. Clear your mind by focusing on the way your hand rises and falls according to your inhales and exhales. Continue to breath this way for five minutes, notice how you physically feel. Has your body started to feel heavy? Are the muscles beginning to relax? Continue on like this until you feel completely relaxed.

#### **4-7-8 Relaxing Breath**

To start, position your tongue so the tip is resting against the top of your mouth, directly behind your front teeth. Keep it there throughout the exercise. Take a deep breath, exhale through your mouth fully, make a whooshing sound as you do so. Then close your mouth and inhale through your nose for a count of four. Hold your breath for a count of seven. Exhale through your mouth, again making the whooshing sound - this time do it for a count of eight. Repeat this three more times. You may find it challenging to hold your breath for full counts the first time – that's okay! It's the ratio of breaths that is important, so count faster until you feel able to work your way to the slower count. Practice this twice a day and within a few months you should notice your ability to fall asleep noticeably improved.

#### **Visualization**

Visualization, or guided imagery, is a variation on traditional meditation. It involves you imagining a scene in which you feel safe and at peace – this involves being able to let go of any stress or anxiety that you may be feeling. You choose whatever setting is most calming to you, real or imaginary, and use the following questions as a guide to help you bring it to life in your mind:

- **Look** around you in that place, notice the colours and shapes. What else do you notice?
- Now pay attention to the sounds around you. What do you **hear**? Or is it silent? What are the sounds far away and those nearer to you, those that are more noticeable and those that are more subtle.
- Think about any **smells** you experience.
- Then focus on any skin sensations – what do you **feel**? The earth beneath you or whatever is supporting you in that place, the temperature, any movement of air, anything else you can touch. Notice the pleasant physical sensations in your body whilst you enjoy this safe place.
- Do you **taste** anything?

For example, if you are thinking about a dock on a lake:

- **See** the sun glistening on the water
- **Hear** the birds singing, motorboats, children laughing
- **Smell** the pine trees, BBQ and grass
- **Feel** the cool water on your bare feet and droplets splashing onto your face
- **Taste** the fresh, clean air

If you struggle to think of a setting in which you feel calm, you can use the example above, or perhaps think of the last time you felt truly happy and content. You can also choose to use listening aids such as soothing music that matches your setting.

Don't worry if you find yourself zoning out or losing track of where you are during a visualization session. This is normal. You may also experience feelings of heaviness in your limbs, muscle twitches, or yawning.

## Exercise

Exercise is a common form of self-care. It promotes better sleep, reduces tension and depression, and increases energy and alertness. It may be hard for you to find the time for exercise but studies have found that as little as 20 minutes of walking three times a week can help to not only maintain your physical health but also help to relieve psychological tension.

There are always opportunities within Hackney to participate in free or low cost exercise classes or physical activity. Check out Healthy Hackney on [www.hackney.gov.uk](http://www.hackney.gov.uk) for more information. You can also discuss exercise options with your GP who can refer you to the GP Exercise Referral Scheme.

## Mindfulness

As a carer, you may find yourself vulnerable to feeling stressed, worried or worn down physically, psychologically or emotionally by the demands of your caring role. Mindfulness can be enormously beneficial because rather than worrying about the future or dwelling on the past, mindfulness switches the focus to what's happening right now, enabling you to be fully engaged in the present moment.

Mindfulness exercises have been used widely to reduce stress, anxiety, depression, and other negative emotions. These exercises range depending on the outcome which you wish to achieve. Some bring you into the present by focusing your attention on a single repetitive action, such as your breathing or a few repeated words. Other forms of mindfulness may encourage you to follow and then release internal thoughts or sensations.

Below are 5 simple Mindfulness exercises which you can try:

### ***Mindful Breathing***

You can do this exercise standing or sitting up, whichever is more comfortable for you.

1. Breathing in through your nose and out through your mouth, letting your breath flow effortlessly in and out of your body. Each breath cycle (inhalation and exhalation) should last for about six seconds.
2. Let go of your thoughts. Let go of things you have to do later today or caring tasks that need your attention. Simply let thoughts rise and fall of their own accord and concentrate on your breath.
3. Purposefully watch your breath, focusing your sense of awareness on its pathway as it enters your body and fills your lungs.
4. Then observe your awareness as the breath works its way up and out of your mouth and leaves your body.

Try doing this for one full minute, and increase it incrementally to five minutes.

### ***Mindful Observation***

This exercise helps you to notice and appreciate elements of your environment. It is designed to connect you with your environment, something that is easily missed when you are consumed with the demands of your caring role. It requires you to slow down and stop – something which many carers find hard to do.

1. Choose an object from within your immediate environment and focus on watching it for a minute or two. This could be anything a chair, tree or even the clouds.
2. Don't do anything except notice the thing you are looking at. Simply relax into watching for as long as your concentration allows.
3. Look at this object as if you are seeing it for the first time.
4. Visually explore every aspect of it, and allow yourself to be consumed by its presence.

### ***Mindful Awareness***

This exercise is designed to cultivate a heightened awareness and appreciation of simple daily tasks and the results they achieve. As a carer you do so much for the PwD and sometimes you may forget the positive impact that simple tasks or chores have.

Think of something that happens every day more than once; something you take for granted, like filling and turning on the kettle to make a cup of tea. At the very moment you turn on the faucet to fill the kettle, stop for a moment and be mindful of where you are and how you feel in that moment. Appreciate what that moment means, or what the outcome (in this case the cup of tea) means.

This pause to appreciate is known as a 'touch point'. If you choose to practice this form of Mindfulness, make sure you pick a touch point that resonates with you for that day and, instead of going through the daily motions on autopilot, take occasional moments to stop and cultivate purposeful awareness of what you are doing and what these actions bring to your life.

### ***Mindful Immersion***

The intention of this exercise is to create happiness in the moment and escape the pressures that we put ourselves under on a daily basis. Rather than anxiously wanting to finish an everyday routine task in order to get on with doing something else, take that regular routine and fully engage in the experience.

Imagine you are cleaning your house, an activity which you normally find to be time consuming and unenjoyable. Now instead of labouring through and constantly thinking about finishing the task, become consciously aware of what you are doing and fully immerse yourself in the progress. Notice your actions; feel and become the motion when vacuuming, sense the muscles in your arms and hands when washing the dishes, maybe think of a new way to organise items

This may sound a little bit silly but the idea is to get creative and discover new experiences within a familiar routine task. By doing so you will get a bit of a break from your normal routine and can give you some much needed headspace.

### ***Mindful Appreciation***

In this last exercise, all you have to do is notice 5 things in your day that usually go unappreciated. These things can be experiences, objects/things or people; it's up to you (use a notepad, or your journal and write them down before the end of each day). The point of this exercise is to simply give thanks and appreciate the seemingly insignificant things in life, the things that support your existence but rarely get a second thought.

If you think that you need a little more support and guidance to develop a Mindfulness practice there are low cost or free apps (visit the app store on your phone or tablet) and websites that you can access such as:

## Websites:

- Yoga Nidra Network
- Loving Kindness Meditation
- UCLA Mindful Awareness Research Centre

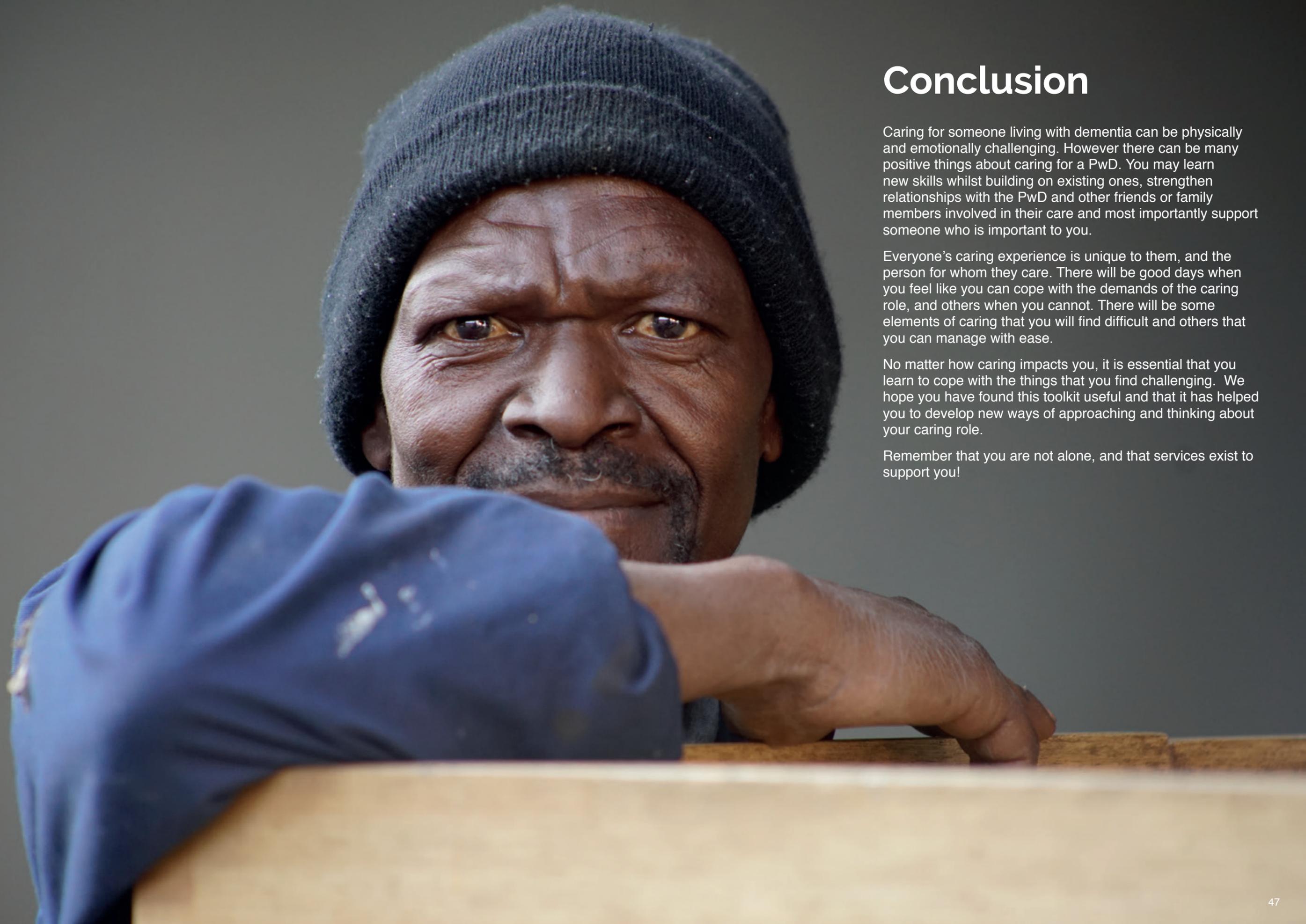
## Apps:

- Stop, Breathe, Think
- Inscape
- Simple Habits
- OMG I can Meditate
- Sattva
- Smiling Mind

## Ask for Help

There are times for all of us when life seems too much like hard work, but when you're caring for others and struggling to find time for yourself, you may find you hit your limit quicker. Surrounding yourself with a support network or taking action to introduce more self-care is essential to preventing burnout. If, however, things do begin to feel too much, don't hesitate to seek professional support. Having someone like a counsellor to speak to can help you process the complicated emotions that often come with a caring role and allow you the headspace you need to keep going.

The East London Foundation Trust Improving Access to Psychological Services has launched Talk Changes, a free confidential NHS service for residents registered with a GP in the City and Hackney. It offers a range of psychological therapies for people experiencing common mental health problems such as depression and anxiety. This is a great tool for carers of PwD who wish to access talking therapies but might not have the time to attend regular therapy or counselling sessions. You can self-refer by going to <https://talkchanges.org.uk/> or talk to your GP.



## Conclusion

Caring for someone living with dementia can be physically and emotionally challenging. However there can be many positive things about caring for a PwD. You may learn new skills whilst building on existing ones, strengthen relationships with the PwD and other friends or family members involved in their care and most importantly support someone who is important to you.

Everyone's caring experience is unique to them, and the person for whom they care. There will be good days when you feel like you can cope with the demands of the caring role, and others when you cannot. There will be some elements of caring that you will find difficult and others that you can manage with ease.

No matter how caring impacts you, it is essential that you learn to cope with the things that you find challenging. We hope you have found this toolkit useful and that it has helped you to develop new ways of approaching and thinking about your caring role.

Remember that you are not alone, and that services exist to support you!



City & Hackney Carers Centre

# Dementia

## Discussions

