For a person who loves and cares for someone living with dementia and is also known as a

DEMENTIA CARE HERO

Careblazer Guide Gwithledyr (Cornish)



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After my late wife was diagnosed with Vascular Dementia, the only support that I was given were booklets by Age UK, Dementia UK and Alzheimer's Society amongst others.

All these booklets concentrated on explaining what Dementia was and how it was likely to progress. There did not seem to be any help for the carer.

Luckily I found a carer's support group in Penzance and it was obvious that we all had the same feelings and also a lack of knowledge of how to look after ourselves in order to support our loved ones.

Loving and caring for someone with dementia is challenging.

No one asks for their loved one to be diagnosed with dementia. It just happens. All of a sudden, it seemed like my world was turned upside down. I found myself responsible for things I never had to do before and was scared about what the future looked like for me and my wife.

Like other carers I found myself facing struggles such as:

- Wondering how much longer I will be able to provide care
- Wondering where to turn for help and how to ask for help
- Wishing my loved one would stop saying mean things and stop accusing me of things that aren't true
- Feeling all alone with no one who understands
- Feeling guilty for losing my temper or wishing it was all over
- Noticing that my personal relationships with others slipped away and I stopped doing the things that I enjoyed.

Whilst researching for information on how to cope with the situation, I came across a website hosted by Dr Natali Edmonds. The information seemed to be exactly what I wanted although it was USA centric.

I entered into discussions with Natali and the outcome was the Cornish Careblazer booklet.

The tips help carers interact and communicate with their loved one with dementia. The tips are designed specifically for people with dementia and are often the complete opposite thing you would naturally consider, which is precisely why the tips are really important.

Copies have been circulated within the memory loss community in Cornwall and it has been found that if one uses these approaches then the interactions with the loved one is more enjoyable and relationships improve.

Less frustration, more joy is the aim of the booklet and I hope that it helps you

Hello Careblazer,

This guide is based off my original work from over 10 years of working with older adults with dementia and the family members caring for them. Although most of the material is the same, this edition has been adapted specifically for the Cornish population.

You can download the original guide at www.careblazers.com which will grant you access to several emails where you can learn even more about the lessons in this guide.

The word Careblazer is a word I created. It means "a dementia care hero." A person who loves and cares from someone with dementia. Thank you for all that you do as you care for someone with dementia. I hope this guide helps you along your care giving journey.

To learn more about me and the work that I do visit me at my website and watch my videos on the Careblazer TV YouTube ⁻ channel. There are over 100 videos to help you as you care for someone with dementia.

With Love Dr. Natali

THIS GUIDE HAS BEEN BASED ON THE WORK OF DOCTOR NATALI EDMONDS AND WE ARE GRATEFUL FOR HER PERMISSION TO LOCALISE THE CONTENT IN ORDER TO MAKE IT MORE RELEVANT TO OUR COMMUNITY

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PREPARE FOR THE JOURNEY

As David has already alluded to, loving and caring for someone with dementia can be challenging. I'm guessing I don't need to tell you that. If you are reading this, then you've probably already had a taste of the struggles that come along with caring for someone with dementia.

No one asks for their loved one to be diagnosed with dementia. It just happens. All of a sudden, it seems like your world has turned upside down. You find yourself responsible for things you never had to do before and you are scared about what the future looks like for you and your loved one.

If you are like many other Careblazers, you may have found yourself facing struggles such as:

- Wondering how much longer you will be able to provide care
- Wondering where to turn for help and how to ask for help
- Wishing your loved one would stop saying mean things and stop accusing you of things that aren't true
- Trying to convince your loved one to shower or change clothes
- Feeling all alone with no one who understands
- Feeling guilty for losing your temper or wishing it was all over
- Noticing that your personal relationships with others have slipped away and you have stopped doing the things that you enjoy

If you have had any similar concerns, then this guide is for you. In the pages that follow, I am going to share common dementia symptoms and how to

respond to help you feel less stressed AND to improve your loved one with dementia.

We have to learn about the disease and enter their reality in order to make the biggest impact and have the most success.

Before you proceed, I have to give you my full honest warning. Even though your loved one with dementia is the one with the disease, the biggest way to help improve your loved one is to change yourself.

GASP! Yes, you have to change in order for your loved one to improve.

I know it doesn't make much sense at first, but this is reality when you love someone with dementia. It's what you have to do if you want your loved one to be as calm and happy as possible. It will make your life much easier as a result.

In order to improve ourselves AND our loved ones, we must understand some basic things about the disease. The things that your loved one with dementia does that seem to make no sense and drive you crazy will all of a sudden make more sense. When we have a good understanding of the disease, then we are able to understand how to respond.

I promise you are not alone. Many Careblazers around the world started out feeling overwhelmed, frustrated, and depressed. They felt like they were at the end of their rope and that there was no hope for their situations. Once they started changing their approach and using the information provided in this guide, their loved ones with dementia started to improve and their own health started to get better.

I encourage you to take the chance on improving your situation. If you are tired of your current situation and are ready to make a change, then continue reading. In the next chapter, I'm going to explain why your loved one with dementia seems to purposefully giving you a hard time.

UNDERSTAND



No, your loved one isn't purposefully trying to drive you crazy. I promise! Sometimes, it can feel like your loved one is literally trying to drive you crazy. Why else would they insist on not showering, insist they can continue driving, or constantly accuse you of things that aren't true? In some cases, your loved one may even blame you for their struggles!

Have you ever tried to convince your loved one to change their mind?

Have you ever tried to convince your loved one to do something they didn't want to do?

Have you ever tried to correct your loved one when they said something that wasn't true?

I'm guessing if you have ever tried to do any of the above things, it didn't go smoothly. Why do you think that happened?

Many Careblazers think that their loved one is in denial. In a minute, I'll explain why that isn't actually true and why we cannot respond to our loved ones with dementia in the same way we would respond to people without dementia.

When you understand what is happening with the disease process, then you understand that the way you have been responding to your loved one has actually been making the situation worse! You can't interact with your loved one with dementia like you interact with others. You must learn a new way to communicate. Once you learn this new way of communicating, your situation will significantly improve.

So, what is happening? Why does your loved one argue with you when you remind them they can no longer drive?

Why does your loved one refuse to do the basic things like change their clothes or take a shower?

Why does your loved one seem to treat you worse than others when YOU are the one that does so much for them?

Let me explain. It's not denial, it's something called anosognosia. This is a process in dementia where your loved one's brain does not have the ability to understand the problems they are having. The term anosognosia means "lack of awareness." It literally means your loved one does not have the ability to be aware of their disease and all of the problems their brain is having. It's a common symptom in dementia.

Because your loved one is not capable of being aware of their problems (no matter how much you try to explain), they see YOU, as someone who is just getting in the way and preventing them from doing the things they want to do. Instead of seeing you as someone trying to help and keep them safe, they see you as someone who treats them like a baby.

Here's an example:

Your mum with dementia is no longer able to manage her finances.

She forgets to pay the bills, pays the wrong amount of money, and is sometimes even scammed out of money from people calling the home.

However, your mum doesn't believe this. Even when you show her the overdraft fees, the late payments, the proof of scams, she STILL does not believe you. Instead, she makes up reasons for the things you are pointing out (i.e., someone hacked her account, you are stealing her money, the banks are corrupt, etc.).

Your mum now starts to resent you. She accuses you of trying to steal her money! The more you try to explain the situation, the more she mistrusts you and argues with you. She has even started to hide money from you and make financial decisions behind your back. After all, in her mind, you are trying to take away control of her money for no reason!

Do you see how this can lead to resentment, anger, and frustration for both you and your loved one?

Anosognosia is the reason that your mum doesn't believe you. This is why no matter what you say, no matter how much evidence you have, and even if you are able to physically prove your point, your loved one does not budge in their belief.

So, what the heck are you supposed to do to avoid the arguments and frustration if your loved one will not believe the truth no matter what you tell them?

For starters, you need to learn a new way to communicate with your loved one that does not highlight their weaknesses because they are not capable of even being aware of those struggles!

You also need to stop trying to argue, correct, reason, and rationalise with your loved one with dementia. The more you try to explain, the more frustrated you and your loved one become.

You cannot make a blind person see. And many times, you can't make someone with dementia reason. The brain simply doesn't have that capability. So, stop communicating with your loved one as if their brain is working perfectly.

In the next chapter I share my top dementia survival tips that will help avoid the pitfalls of correcting, arguing, and reasoning with your loved one with dementia.

SURVIVAL TIPS



The tips below are a few of my favourite Careblazer approaches to help you interact and communicate with your loved one with dementia. These tips are designed specifically for people with dementia and are often the complete opposite thing you would naturally consider, which is precisely why these tips are really important.

If you use the approaches below, your interactions with your loved one will be more enjoyable and your relationship will improve. Less frustration, more joy. Right on!

Ready to improve your relationship with your loved one? Here we go!

Tip #1: THE COMPASSIONATE LIE

This tip really starts to get into the nitty gritty of how interacting with someone who has dementia is so much different than interacting with someone who does not have dementia. Many people feel very strongly when they think about lying to someone. They are taught that lying is wrong and should be avoided at all costs.

In dementia, "lying" is sometimes the kindest thing you can possibly do. Stick with me here.

When people think of lying, they think of the traditional reason to lie- to deceive someone, usually so they can get some type of personal gain. In dementia, a compassionate lie is not meant to deceive it is meant to <u>relieve</u>.

Let me say that one more time. Compassionate lying is not meant to deceive, it is meant to relieve.

If the truth about something is bringing your loved one with dementia significant anxiety, worry, or pain, what can you do to relieve that pain?

Example: Your dad with dementia has not worked in over 10 years. He wakes up every morning and starts to get ready for work.

<u>Caregiver Response:</u> "Dad, you don't work anymore, remember? You stopped working 10 years ago."

<u>Careblazer Response:</u> "Dad, the boss called, you have the day off from work today! Let's go for a walk."

Reminding your dad that he doesn't work anymore is going to make him either... #1. Not believe you and continue to get ready #2. Feel anxious that he no longer works and didn't remember that or #3. Feel sad because the thing that he did for so long no longer happens.

Instead of viewing lying as all bad, I want you to think of your reason for lying. Is it to relieve your loved one's pain or is it for personal gain? If it's primary cause is to relieve your loved one's pain, then by all means, do it. This is going to save you and your loved one so much heartache.

Here's another example of when a compassionate lie can help.

<u>Example:</u> Your husband has dementia and is no longer safe to drive. You are getting ready to drive to a doctor's appointment when your husband says, I'll drive.

<u>Caregiver Response:</u> "You can't drive anymore, you have dementia and the doctor said you aren't safe." This is likely to lead to arguments, resentment, and frustration.

<u>Careblazer Response:</u> "I actually feel like driving today. Let me chauffeur you around." Smile, open the passenger door for him, and motion for him to go inside.

The Careblazer approach is much more likely to avoid arguments and does not make your loved one feel bad for reminding him of something he is no longer able to do.

Whether you have dementia or not, no one likes to be reminded of what they can't do. Because there are many things that may pose a safety risk for people with dementia, it can feel that much of what you say to your loved one is negative or a reminder of their disease. Get creative, think of things you are able to tell your loved one that reduces the chances for anxiety, sadness, and anger.

Whatever you do, resist the urge to argue, correct, or reason with your loved one.

Tip #2: CHOOSE YOUR BATTLES

There will be MANY things that your loved one says and does that do not make sense, that are wrong, or may be completely strange.

Before you correct your loved one, ask yourself, "Is it necessary for me to correct?" (think of a Careblazer saying to use here).

There will be many struggles along your caregiving journey and it is up to you to decide which ones you want to focus on and which ones are better left alone. If your loved one insists that the chicken they are eating for dinner is pork, let it be. If your loved one insists on wearing a princess crown when they leave the house, then by all means, let them be a queen. If your loved one tells you that they were the prime minister, nod your head and smile. Not only is this approach super helpful to you, it will be super helpful to your loved one.

There is no need to correct or challenge. <u>Bottom line: You will need to save</u> your energy for the more important things.

Careblazer Rule of Thumb: If what your loved one is saying or doing is not a safety risk, then let it be. This will improve your relationship with your loved one AND reduce your level of stress since you aren't constantly correcting them.

Ask yourself, would you rather be right or would you rather be happy?

Get familiar and know what could be coming. The more you recognise the challenges as part of the disease, the easier it will be for you to deal with the challenges when they happen. Please note that I am not saying caring for someone with dementia is easy or will ever be easy. Loving someone while watching them drift away in front of your eyes is one of the hardest and most

heartbreaking things. But preparing yourself and getting informed about the disease will help you feel more in control, it will help you think of ways to respond, and it will help you realise that you are not alone.

Tip #3: JOIN THEIR WORLD

Sometimes, we try to respond to our loved ones with dementia, the way we would respond to people without dementia. Quickly you will find that this approach does not work most of the time.

IT'S NOT ABOUT MAKING SENSE IN YOUR WORLD, IT'S ABOUT MAKING SENSE IN THEIR WORLD.

As humans, we immediately jump to trying to explain or rationalise with our loved ones with dementia only to find out that it backfires on us. In order to know the best way to respond to your loved one with dementia, you have to take the time to view things from their perspective. Remember, their brains are slowly dying and they are not able to understand much of the information that we are so fortunate to understand. What seems like a completely reasonable explanation to us, may not make any sense at all to someone with dementia.

Example: You are caring for your mum with Lewy Body dementia.

She is terrified every time she wakes up and yells that there are people watching her.

<u>Caregiver Response:</u> "Mum no one is watching you." You don't understand it and tell her everything is okay and there is no reason to be afraid. Your efforts to talk to her don't help. She continues to insist every morning that there are people watching her. You are frustrated that your mum isn't listening to you and your mum continues to be scared every morning.

<u>Careblazer Response</u>: "It's okay, mum. I'm here. You are safe." You now take time to enter her world. You take what you know about dementia and look around the room. You notice that there is a mirror right next to her bed and realise that when she wakes up and sees her reflection, she thinks it is another person. You decide to take the

mirror out of the room and now your mum no longer yells that people are watching her when she wakes up. Success!

From your perspective, you understand that no one else is in the room. But from your mum's perspective, she cannot understand that. You can either continue to try to convince her and be frustrated every morning, or you can take the approach of joining her world and getting creative with your response.

IF YOU WANT YOUR LOVED ONE WITH DEMENTIA TO CHANGE, THEN <u>YOU</u> ARE THE ONE THAT HAS TO CHANGE.

Tip#4: YOUR BEHAVIOUR IS MORE IMPORTANT THAN YOUR WORDS

In dementia, the ability to understand words gets harder and harder. Because of this, your non-verbal behaviour becomes more important than ever. You are basically a mirror to your loved one. Whatever emotion you are showing on your face, will be the emotion your loved one with dementia shows back to you. If you look stressed, nervous or frustrated, then your loved one with dementia will likely be stressed, nervous, or frustrated.

This is good news! This means that if you look happy, calm, and peaceful, your loved one is likely to be happy, calm, and peaceful. Non-verbal behaviours are often the key to what separates a typical dementia caregiver from an excellent Careblazer.

If your non-verbals are giving messages of stress and frustration, you can pretty much forget about getting your loved one to do anything you want. Your loved one will not be able to focus on what you want them to do because they are going to be stressed.

Situation: It's bath day for your wife with dementia.

<u>Caregiver Response</u>: You are already nervous because this is a stressful experience. You are tense, you face is stressed, and you are talking sternly to your wife to make sure she understands that she needs to get in the bath. You start to help her undress when she hits you and refuses to get in the bath.

<u>Careblazer Response:</u> It's bath day but you tell her it's spa day. You know this is a stressful day for your wife so you make sure that you are in a good mood and mentally prepared for the task. You make sure the bathroom is

warm, her favourite music is playing, that the water temperature is good, and you are constantly smiling and telling your loved one they are okay. Before you start taking your wife's clothes off, you tell her what you are about to do. You move slowly and make sure to smile throughout. Your wife is able to get through the "spa" experience.

Here are non-verbal skills to practise with your loved ones.

NON-VERBALSKILLS

- Nod
- Smile
- Keep your posture and body open and inviting. Your body language is important.
- Look at your loved one when talking.

TRY IT OUT



Take a moment to write down your biggest current struggles and think about ways you can try to respond to them using the information you just learned. Think about joining their world, seeing things through their eyes, and researching or asking others about how they have handled similar situations. Remember: sometimes just changing your own thoughts about the situation and using coping statements can make all the difference. Give it a try.

BIGGEST CURRENT STRUGGLE:

POSSIBLE COMPASSIONATE LIE:

THINGS YOU CAN STOP CORRECTING AND JUST LET BE:

WHAT THINGS ARE YOU TRYING TO CHANGE THAT YOU DON'T NEED TO CHANGE?

NON-VERBAL BEHAVIOURS TO START USING:

SEE IT FROM THEIR POINT OF VIEW: How may your loved one be viewing the situation?

WHAT OTHER POSSIBLE REASONS MAY BE CAUSING THEIR BEHAVIOUR? Consider pain, hunger, boredom, anxiety, need for bathroom, etc.

GET YOUR MIND RIGHT

Sometimes it can feel like your loved one is purposefully trying to drive you crazy. We've already learned that much of your loved one's behaviours are a result of the dementia, and that anosognosia (i.e. lack of awareness), is one of the biggest reasons why your loved one might be resistant toward your attempts to help.

Even though you may know this, there will still be times when you are frustrated and feel convinced that your loved one knows what they are doing. Usually this is because your loved one may have had some similar behaviours before their dementia diagnosis.

Regardless of the reason for your loved one's difficult behaviours, thinking your loved one is purposefully trying to give you a hard time will ruin your ability to provide good care and will increase the chances that your loved one will continue to have difficult behaviours. Your loved one will pick up on your frustration, irritability, and overall negative attitude and this just makes your situation that much harder.

Let me tell you about a proven principle that psychologists world-wide use to help people improve their mood and ultimately improve their lives.

Our thoughts create our feelings, and we act and respond based on how we feel.

Most people think that situations create our feelings, but that is not true. This is why people in the same situation feel and act different ways. The thing that makes the difference? Our thoughts.

Some of you reading this may be asking, "How on earth could changing my thoughts actually lead to any change with my loved one? I just need my loved one to change. My thoughts have nothing to do with changing them." Let me explain with a simple example.

<u>SITUATION</u>: Your mum lost her purse again and is yelling that you stole her purse.

<u>THOUGHT</u>: "She's such a liar! I can't believe she has the nerve to accuse me of stealing her purse after everything I do for her!"

FEELING: Anger.

<u>BEHAVIOUR</u>: You snap back at your mother. The rest of the day is tense with little communication. Your mother chooses not to eat dinner that night.

<u>SITUATION</u>: Your mum lost her purse again and is yelling that you stole her purse.

<u>THOUGHT</u>: "Her mind is trying to understand how her purse is missing again. What an awful disease."

FEELING: Compassion and understanding.

<u>BEHAVIOUR</u>: You tell your mother you that you love her, will help her find her purse and then you two engage in a pleasant activity together.

Do you see how the situation was the same (your mum accused you of stealing her purse), but <u>your feeling and actions afterwards were different</u> <u>based on what you thought about the situation</u>? This is a really quick example to show how our thoughts are important and to hopefully encourage you to be mindful of your thoughts.

For dementia caregiving, we can take this diagram a step further. Because people with dementia pick up on your emotions and facial expressions more than they do your words, your actions (which are influenced by your thoughts) will start to change your loved one...either for the better or for worse.



Our thoughts become our reality so if you think to yourself, "*My dad is always doing things to drive me crazy*!" Guess what? Your dad will probably always seem to be doing things to drive you crazy because your feelings, facial expressions, and actions will trigger your dad to act in those ways.

Instead, if you think "*This disease is really hard on my dad and I know it's not his fault. I'm frustrated but I understand.*" Guess what? You will be calmer and more understanding of your dad's difficult behaviours. As a result, your dad's behaviours will reduce because your feelings, facial expressions, and actions will help your dad feel more comfortable.

Now you understand your thoughts can impact your mood and behaviour, AS WELL AS, your loved one's actions. Because you understand the relationship between thoughts and feelings, it doesn't mean that you aren't going to find yourself completely frustrated and thinking negative thoughts.We are all human and those moments are completely natural.

However, it is not okay to let those negative thoughts hang out in your mind and simmer. When you notice that you are having a negative thought toward your loved one, you want to be able to replace those thoughts with something that will be more helpful for you AND your loved one.

You know hard moments are coming, that is a reality. It's important to know how to get through those tough moments. On the next page, I've included some examples of coping statements to give you an idea of things you can say to yourself when you feel like you are about to lose all control. These simple statements take no time, and hardly any effort to do when you are feeling at your wits end. Don't mistake simple for not worthwhile. These statements can truly make a difference, but they only work of you put them to work.

Take a look at the list on the next page and see what kind of style matches your style of thinking. Then, try to create your own coping statement.

As a Careblazer, you need to be aware that your thoughts can actually influence your loved one's behaviour – for better or for worse.

Your loved one is not trying to give you a hard time. They are having a hard time.

SAMPLE COPING STATEMENTS

Think matter of fact:

"Yes, here it is. I knew it was coming and I know that it is a part of the disease."

Think funny:

"Well, it's good to know mum's mouth still works, even if her brain doesn't."

Think calmly:

"Just breathe. Nice and easy breaths, I know that I will get through this moment."

Think future:

"I really don't like this, but I know one day he won't be around to say anything at all."

Think honestly:

"I am so sick of this sh*t, but I will get through it no matter how hard the days!"

Think like you: What can you picture yourself saying in your mind that would be helpful in getting you through the difficult moments? Use words that you can hear yourself saying. Remember, this is just in your mind so you can be as true to yourself as you want without fear of anyone else knowing. Write your statement below.

SELF-CARE EXCUSES

Let's take a moment to talk about the many reasons that make it difficult to take time to care for yourself.

I AM TOO BUSY

It's true. You probably are too busy. Loving someone with dementia takes up a lot of time and many of you are also trying to juggle caring for your loved one with dementia AND your own children, job, spouse, parent, pets, etc. **IT IS A LOT**. But taking care of yourself doesn't have to take up all your time. In fact, you can still do everything you are currently doing **AND** find little, simple ways to be kind to yourself during the day. Examples include:

- Take some deep breaths
- Enjoy a moment of peace in the shower and use a new body wash
- Pick up the phone and talk to a supportive friend while you wash the dishes or fold laundry (hands free device of course)
- Go for a short walk
- Paint your nails or get your nails done
- Journal
- Meditate
- Visualise a happy or calming scene
- Watch a funny TV show or movie
- Listen to some of your favourite music when you get ready for the day
- Take time to eat healthy food that will give you energy and make your feel good

You do not need a big chunk of time for self-care. You can take advantage of the brief moments throughout the day and enjoy the mini-breaks.

Notice how many of these activities could be done when you are physically still with your loved one (watching TV, taking deep breaths, going for a walk). Other activities, are things you are already doing during the day but you are now making more of an effort to make it a quality time for self-care (music when you get ready, using a new body wash in shower, etc.). These are things that are not going to take up any more of your time. **It's about using the time you already have in a way that supports you.** If possible, look into options for having people come to your house and give you a break so you can do even more for self-care.

I FEEL GUILTY

Many dementia caregivers struggle with taking time out for themselves. In their mind they think that taking time for themselves is selfish and makes them a bad caregiver. The complete opposite that is true. Taking time for yourself is actually one of the best things you can do for your loved one with dementia!

Be honest. Right now, stop and ask yourself what would happen to you if you were all of a sudden too sick to care for your loved one? What would happen to your loved one? If you did not change one thing about your self-care and 3 years went by, what would your life look like? Would you somehow be in a better position, the same position, or would you be worse? Sometimes, it takes getting real honest with yourself to realise that not giving yourself the care you deserve has a pretty scary future for you...and your loved one.

Self-care isn't selfish!

WHAT WILL OTHERS THINK OF ME?

One of the things I tell myself over and over is that **it is none of my business what other people think.** You may find it helpful to think the same thing. You cannot live your life worried about what other people think because that would be a pretty awful life. Besides, when it comes to the stress of loving someone with dementia, it is important to surround yourself with people who support you and want to see you take care of yourself. Loving someone with dementia is hard enough without people around you bringing you down. People who would think something bad of you for taking care of yourself are 1) not the supportive people you need in your life and 2) probably have no idea what it is like to love someone with dementia. If you really want to shut them up, offer to let them take care of your loved one for a while. Okay, I'm just joking on that last part but I bet it would work! ;)

I HAVE NO HELP

Many times, people feel all alone when caring for their loved one with dementia. There aren't too many people eager to spend their free time caring for someone who most of the time doesn't realise they need the help, or doesn't want the help, or resents you for giving the help. It can often feel like a lonely and thankless job. However, you might be surprised at the help you can get if know how to ask for help or accept help when it is offered.

Many times, when a neighbour or friend, or co-worker asks if there is anything they can do for help, the usual response is a passive, *"No thanks. I've got it handled, it's just hard."*

It's okay to say, "You know what, it would be really helpful to have someone sit with my mum for an hour while I ______." You can fill in the blank with whatever you want. Or you can say, "That is so kind of you. If you ever have any leftover dinner, it would be a big help to save me from having to cook dinner one night." Most times, the people who care about you want to help but they just don't know what to do or what would be helpful. It's okay to give them suggestions, after all, they are asking.

If asking for help seems too uncomfortable to you, then keep this in mind the next time your birthday comes around or when the holidays come around. This is the time of year, people expect you to have some ideas for what you want/need. Consider asking for someone to give you a break for a few hours, or a gift card to a nearby restaurant so you won't have to cook dinner.

In addition to asking for help or accepting help when it's offered, you also want to get to know the resources in your community that can offer help to you. Some of the most common resources include:

Online support groups: There are many support groups online. Do a Google search for online dementia support groups to see what pops us. Also, make sure to join the Dementia Careblazer Community- a closed FB group for Careblazers to support one another!

In person support groups:

Contact your local Memory Cafe, Carers Group or Dementia Friendly Community Group

Adult day health care centres:

A safe place for your loved one to spend time during the day to give you a break.

Look up Cornwall Link at https://cornwall-link.co.uk/ where you will find a lot of useful contacts.

For a list of Memory Cafes in Cornwall visit www.cornwallmemorycafes.co.uk



SIMPLE THINGS I CAN START DOING TO IMPROVE SELF-CARE:

WHAT WILL I TELL MYSELF WHEN I FEEL GUILTY FOR TAKING TIME FOR MYSELF?

HOW CAN I ASK FOR HELP IF I WANT A BREAK?

IF SOMEONE ASKS ME WHAT THEY CAN DO TO HELP, THIS IS WHAT I WILL SAY:

WHAT LOCAL RESOURCES ARE AVAILABLE IN THE AREA ?

CAREBLAZER SURVIVAL GUIDE CHECKLIST



Preparation: I understand that the disease makes my loved one act in challenging ways and I do not take it personal. I am able to respond to them in ways that help them feel calm and safe. I don't argue or try to convince my loved one of something they don't believe.

- I am creative in how I handle challenges.
- I talk to other Careblazers to see how they cope with similar challenges.
- I am aware of how my behaviour, non-verbals, and thoughts can make the situation better or worse.



Mind set: I know there will be difficult times, but I am ready and able to face them without letting them tear me down. I also know there will be some good times and I will take time to cherish those moments.

I am prepared with coping statements.



Refresh: I put myself first because I know it makes me a better Careblazer.

- I take time for myself. The time I take caring for myself will make the time I spend with my loved one better, easier, happier.
- I remember that I have a life to live even after my loved one is gone. What kind of life will that look like for me if I don't start taking care of myself now?





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Contact us

www.cornwallmemorycafes.co.uk



working in partnership with disAbility Cornwall & IoS