

Adult and Later Life Care – Emotional Support for Carers

When supporting a loved one in through their care journey, it can often take an emotional toll on both them and anybody providing care and support for them. A common question raised by family members is “how do I raise the topic of care?” or “I can tell that they need professional care, but they are refusing all help, what can we do?”.

There often isn't a straightforward answer to this. If someone is considered to have mental capacity then it will always be their choice as to whether they accept help, regardless of the concerns of their loved ones. However, there are some steps you can take to help encourage a more open and productive conversation about care options.

This document gives some suggestions on how to approach conversations around certain topics and how to protect your own mental health.

A summary of our top points to consider:

- Have conversations about care options early, preferably before a person requires assistance.
- Involve the person requiring care throughout the planning and decision-making process, giving them choice.
- You may find it beneficial to involve a third party, such as the person's GP. Speaking with an independent person who is considered an 'expert' may encourage the person to accept help.
- Take the time to care for yourself. It is very common to have feeling of guilty or stress when supporting a loved one through this journey.

We discuss these points, along with many more, in the four chapters below:

Chapter One - Managing your emotions

It's easy to fall foul of negative emotions when helping loved one through a medical or care journey.

Perhaps you have had to enlist help with supporting a loved ones and feel like you have failed caring for someone? Perhaps those needing your support are causing you to feel guilty if you have to re-prioritise and cannot always see them every single day? Perhaps realisation that sometimes it's just too much for one person to deal with makes you upset, especially if loved ones are uncomfortable with a particular course of action you need to take? Determining where these feelings are coming from can also be a challenge.

Learning to manage guilt and other negative feelings starts with identifying its source. Some questions you can ask yourself to help understand the root cause of those emotions include:

- What happened to cause this feeling?
- What specific aspect of this do I feel bad about?
- Did I *actually* do something wrong, or am I just *perceiving* I did something wrong?
- Is someone else making me feel guilty?
- Is it in my control to fix the situation?
- Could fixing the situation help?

The answers to these questions may help you understand where these feelings are rooted and the best way to manage them. If you have difficulty managing negative emotions, it might be helpful to talk with a mental health professional about your concerns. Once you understand why you feel the way you do, the next step is to figure out how to manage it. Consider trying some of these strategies.

Acknowledge it exists - Identifying your emotions and why you may feel them help you figure out the next steps you need to take.

Eliminate negative self-talk - Though negative emotions such as guilt can initiate positive action, it can also cause you to associate your behaviour with who you are as a person. This can lead to inaccurate self-assessment. Try to remind yourself that although your actions or behaviour may have caused a negative feeling, it does not define you as a person.

Find out if there's a reason to feel the way you do - Negative emotions can at times be unwarranted because the person involved has moved on from the incident or has already forgiven you. So, think about asking the person how they really feel. You might be surprised to find out that you've been carrying guilt or feelings of letting someone down for no reason.

Remind yourself of all that you do - When feeling negative, you might have trouble remembering all the positive things you do. Consider making a list of all the acts of kindness and care you have achieved; you will likely always find that the number of positive actions on the list far outweigh any negative points.

Realize it's OK to have your own needs - Guilt is often rooted in the worry that you're selfish with your time, money, or energy. However, it's helpful to remember that no one can be everything to everybody all the time. You also have needs, and they're equally as valid as the needs of others.

Make amends - Sometimes, the presence of guilt or other negative feelings may indicate a call to action. Once these amendments are made, remorseful feelings often seem to fade away. If you can no longer make amends to someone, maybe because they are no longer with us, try writing a letter to say what you couldn't say at the time, and then discard it in some way as an act of closure.

Understand what you can control - It can be helpful to review the source of your feelings and determine what aspects you can manage. If nothing can change the situation, bear in mind that holding onto negative emotions is unlikely to deliver the change you are looking for. Some things cannot be changed and that's ok!

Address any mental health challenges - If mental health conditions or past trauma are playing a role in your emotions, it might be a good idea to talk with a mental health professional. They can work with you to identify areas you may need help with and offer strategies to manage your feelings.

Perfection doesn't exist - If you hold yourself to a high standard, and even the slightest infraction leaves you riddled with guilt, it might be beneficial to remind yourself that no one is perfect. **We all make mistakes.** Making mistakes doesn't mean you're a bad person. It simply means that you're learning and growing as you navigate through this thing called life — just like everyone else.

Chapter Two – Moving into a Care Home and Coping with ‘Care Home’ guilt

Even if you have plenty of help from home carers or have time to care for a loved one yourself, there may come a point where accessing full-time care in a residential setting makes more sense.

One of the challenges of transitioning a loved one or spouse into full-time Care is the feeling of guilt. However, if you know in your heart you are making the right decision for them, it's important you find a way to cope with this and do what's right by your loved one.

Sometimes, the challenges of caring for loved ones yourself or through Carers at home reaches a point where it is no longer as effective as it used to be. If their care needs are struggling to be met at home any longer, it may be time to think about moving them to a residential setting, this will ensure they get all the support they need and consistently.

This can often be upsetting and can bring on feelings of guilt and inadequacy of looking after loved ones at home. At this time, it can help to look at all the positives.

Remind yourself that a move into a residential setting means:

- All meals are taken care of – you know your loved one will be eating nutritious meals regularly and it removes the risk of harm through preparing and cooking food
- Medication is administered on time everyday which removes the risk of them being forgotten or excessively taken
- Residential settings provide a safe environment. Specialist equipment for bathing, or rails along corridors for added safety of those unsteady on their feet are good examples of this. They are also secure, providing peace of mind loved ones won't wander into harmful situations, or that they are targeted by cold callers knocking at their door
- There is often a great social environment and a sense of community
- There are typically activities and events to help keep your loved one engaged with enjoying their hobbies
- Staff are around all day and night, meaning your loved one will always be able to access help quickly if needed
- Residents have access to services on site should they be required, such as ophthalmologists, nutritionists, occupational therapists and hearing specialists
- Staff are fully trained and specialise in caring for complex care needs

Aside with managing your own feelings, you need to think about the feelings of your loved one when exploring the conversation about looking at residential care options and the benefits it could bring. Explain your concerns and the benefits considering a Residential setting could have.

If they are refusing to consider going into care, ask them why. The answer may be, "Because I'm afraid I won't see you again." Or "Because I don't want to leave my belongings behind". When you have an idea of why your loved one is feeling reluctant, you can take steps to address their concerns. Taking a tour of a Residential facility is often a good way to break through resistance, so your loved one can see what a lively and welcoming place these care facilities can be.

If talks continue to be met with objections or become upsetting, sometimes it can help to make an appointment with your loved one's GP and attend it with them or have a GP visit

home. Often, the voice of an individual who is less personally attached to the situation can trigger more rational conversations.

Be prepared for a lengthy process. If the GP feels there is a care concern, they may refer you to the Adult Social Care department of your Local Council. They will likely carry out a Care Needs Assessment to assess *what* the Care needs are and what support is required. This can not only help loved ones realise they need support, but also give you potential other options to consider. However, if your loved one is considered to have capacity and still refuses a move, then nobody can force them to do so.

If you've had to put a loved one into a care home, it is common to feel guilt, which can present itself because you feel as if you have abandoned your loved one, or because you feel you didn't do enough. The first step to managing guilt is to identify what provokes the feeling as it will help you to manage it better.

There are different ways you can manage guilt, including realising that your loved one is in good hands in a care home and thinking about the benefits. So, ask yourself: What is actually the best decision for your loved one?

Caring for a loved one is a huge task. It can be difficult to hand over the duty of care and you may feel guilty because you feel your best is not enough. Just remember that caring for a loved one is a big job and if you struggle to cope, helping your loved one move into a care home may be the best for everyone involved. It enables your loved one to receive the care they need and allows you to take care of yourself.

Accepting you can no longer meet your loved one's care needs can help you cope with any guilt. It also helps to remind yourself that Care Homes are full of professional, qualified care workers who will be able to support your loved one around the clock.

Reassure yourself. You are not giving up. You will be able to regularly visit your loved one, still be able to provide support and influence their care, but without the constant responsibility or worry. You can rest assured they are safe and receiving all the care and attention they need.

To help overcome feelings of guilt there are lots of practical things you can try both before and after a move into Care:

- Take the time to visit different homes together until you find the right home and care for your loved one.
- Book a short-term stay before committing, so they can become familiar with the facility and get to know the staff.
- Start the application process a few months before you think it will be necessary (if possible) so you can both be emotionally and physically prepared.
- Remind yourself that your loved one will be properly cared for, around the clock
- Visit your loved one regularly - go out for coffee or on other outings such as the garden centre. Have fun together, enjoy each-others company without having to worry. Try and stick to a schedule so they know when to expect you.
- Call on the phone on the days you can't be there in person.
- Be proactive about their care and stay in touch with the staff.

- Remember - unless you are a nurse or care worker yourself, it can be progressively more difficult to look after a senior, particularly if they have special needs around eating, bathing or taking medication. If they are in experienced hands, they will soon become used to their new residence and community.

Feelings of guilt in this situation are very common, which means **you are not alone**.

Talking about your emotions and receiving support from others can be extremely helpful. If you are struggling for a period of time, it could be worth speaking to a mental health professional to support you.

Chapter Three - Raising Concerns

Raising Health and Wellbeing Concerns

Understandably, it can be upsetting to see someone struggle as their needs increase, especially parents and loved ones. Often, these struggles can be caused by medical conditions, treatment regimes, and even un-diagnosed issues that they may not see as a concern, or even wish to face. So, how do you encourage seeking medical help if you are worried about them?

One of the best things you can do is have a conversation to explore the reasons you are worried and discuss your reasoning, along with what the potential solutions could look like. However, those conversations won't always come easily. It is very important to ensure you both agree on the best way of addressing any concerns, and you must remember to be mindful of your loved one's feelings.

You need to be empathetic and patient. Let's think about it, it can be very unsettling talking about any signs that could suggest you are becoming less able to cope. Emotions such as sadness, embarrassment and guilt of not wanting to 'burden' family members can often lead to loved ones dismissing a problem which should be investigated or treated.

It can also be unsettling for you when trying to help as perhaps you do not want to acknowledge that a loved one's needs are increasing, or you do not want to cause upset or harm your relationship. Feelings like these could lead to you delay having a conversation, and the best way to avoid that is planning.

Before you think about having a conversation with a loved one, it's best to be clear about *what* the problem is. Being clear on *what* you are concerned about and *why* you are feeling this way will help you approach the matter at hand more easily. It is also helpful to think about whether you think your concern relates to a low or high-risk issue.

Low Risk Concerns are usually behaviour related. For example, a loved one not brushing their hair anymore, wearing make-up or putting on clean clothes. Letting the household chores slip, becoming messier than usual and suddenly having no pride in their home or appearance. Small changes to behaviour like this are often the *earliest* signs that something is wrong. If you know the person well, and see them often, you are more likely to notice these subtle changes over those who don't see them as much.

Medium Risk Concerns are also often behaviour linked but could have a detrimental impact on their general health and mental wellbeing. For example, a loved one stops washing regularly, stops getting dressed each day, refuses to go out, interact with others or is not getting a healthy amount of sleep. These changes affect a loved ones' daily routine and are more noticeable - even to other people who are not as close to your loved one as you may be.

High Risk Concerns are those which may require intervention and support to be able to make changes. They relate to changes which can seriously affect their health and wellbeing, and include things like not eating properly, rapid weight changes, drinking lots of alcohol, not taking medications and even living in unsanitary conditions.

Severe Risk Concerns are less common, but sometimes a person can be an immediate risk to themselves, or even others. Examples could be living in a dangerous environment, failing to take care of an injury or illness, or having suicidal thoughts.

These are not easy to address without professional help, so if you're very worried about a loved one and need immediate support, you can either:

- Call the emergency services on 999 if there is an imminent risk of any harm
- Call NHS 111 if you're very concerned about someone's health or welfare, but it is not an emergency
- Contact the local council in the area where the person lives and raise an 'adult safeguarding' concern. This should be done with the consent of the person wherever possible. [Visit GOV.UK to find your local council](https://www.gov.uk)
- If that's not possible, or you feel that seeking consent would create more risk, then you can contact the council without the consent of the person at risk.

Remember, we cannot force someone to accept help. It's good to take a step back and look at the situation objectively. Some things may be less serious than others, but that doesn't make them any less valid and if someone is at immediate risk of harm, you need to act.

Having a Conversation – Top Tips

Your loved one's resistance to visiting a doctor or accepting a problem can undoubtedly be frustrating but keeping your emotions under control is very important. Letting your emotions get the better of you such as getting angry or raising your voice will not help the situation.

It can be difficult to stay in control, but avoiding the following can help:

Lecturing: Lecturing loved ones and using phrases like "you need to do this," "you should have done that" is not motivating. It can cause loved ones to shut down and they are less likely to speak with you. It can also make them feel untrusted or incapable of doing the right thing, which is likely to damage your relationship.

Raising your voice: This makes people feel like they are in trouble and is likely to make them withdrawn and avoid conversations.

Getting too Emotional: Strong emotions make a conversation more difficult to carry out and can cause you to say things you don't truly mean. We have all said things in the heat of the moment and it can become easy to say hurtful things or upset your loved ones without meaning to. Always wait until you're feeling calm before having a conversation, and if things get heated during the conversation, take a pause and revisit it later.

Describing Worst-Case Scenarios: If you're noticing your loved one's health declining, don't go further and describe horrible things that could happen. For example, saying "If you don't visit the doctor - you're going to end up breaking your hip" is not going to achieve much, other than worry and scare your loved one. Instead try sticking to facts such as "I'm concerned you're not seeing the doctor – you have had a dizzy-spells twice this week".

Repetition: Bringing up the conversation too often can come off as nagging. Take it slowly and don't expect your loved one to change their mind right away.

Making Decisions for Your Loved One: It is up to your loved one to make their own healthcare decisions and reach the conclusion that a medical visit is helpful. Try not to be too forceful. Rather, work with your loved one to get them to see the concerns you have.

If you're noticing your loved one's health declining and they still refuse to visit a doctor, remember that there's only so much you can do. Ultimately, if someone is capable of making their own decisions then they cannot be forced to do anything they do not wish to, even if the decisions they are making seem to be unwise.

Raising coping concerns and the need for Care

Care can be a difficult topic to discuss with loved ones. This is because it's not uncommon for those in need of care to associate it with a loss of independence, or even failure – which can bring on stress or other strong emotions. This means that conversations around care often benefit from plenty of sensitivity, patience, and cooperation; as well as a conscious effort to help your loved one see the many benefits of receiving care. Naturally, this isn't always straightforward.

So, to try to make things a little easier it may be useful to consider the following steps.

1. Think about what type of Care your loved one could benefit from. There are various types of care, and each one will be better suited to particular needs and situations. For example, home care, which involves daily visits from a carer, can be ideal for people who can no longer carry out or struggle with daily tasks by themselves, but wish to stay at home. While for someone living with dementia, 24-hour care, perhaps in a residential setting may be better suited.

There are so many care options available, so it is worth taking time to think about which would best suit your loved ones needs. Doing this research before starting a conversation around care with your loved one can help things go more smoothly. *Legal & General's Care Concierge can help you understand all of your options. This service is free to you to use. Please reach out to your HR or Benefits contact for details of how to get in touch.*

2. Have the conversation early. Transitioning from living independently to accepting care or support is often a very gradual process, and something that requires more than a single discussion. With this in mind, there are a number of benefits that can come from starting conversations around care early.

Discussing the idea of care and letting it settle for a little while can allow your loved one time to consider, and perhaps come to terms with the idea of receiving some help. It can also remove the shock, if and when the time comes to properly discuss care at a later date.

Another benefit to discussing care early is that conversations are more hypothetical, which can take away some of the reality and rawness of it. This helps everyone involved to view situations more objectively, without any strong emotional influence.

3. Put yourself in their shoes. Conversations about care can be difficult and emotional. This is because many people associate needing care with a loss of independence and may feel embarrassed, upset, or even ashamed that they can no longer do all the things they used to. For those who've been independent their entire lives, this can be especially difficult or painful to accept.

Take the time to understand and appreciate things from your loved one's perspective and put yourself in their shoes. This can help you approach them with greater empathy, patience, and sensitivity – especially when conversations become difficult or frustrating.

4. Think about your surroundings and pick your time wisely. When the time for discussing care options does come around, it's important to talk in an environment that your loved one feels comfortable in, where you can both relax. This will make it easier for each of you to speak openly, listen, and communicate honestly.

Allow plenty of time for a conversation. This is key, so avoid dropping the topic of care in at the end of a visit or telephone conversation – and instead anticipate that the conversation could be lengthy. It's also worth considering your loved one's mindset when your plan to have a conversation and, where possible, to bring it up at a time when they're feeling more positive. If they're having a bad day or have other worries on their mind, it might be more beneficial to wait.

5. Be prepared to receive push back. While everyone hopes for a simple conversation about care, this isn't always the case. Some people may refuse to accept that they need help, insist that they can manage on their own, or in some cases, even refuse to talk at all. While this can be difficult, it's important to remember that these reactions are completely normal because care is a sensitive topic.

Just remember to reassure your loved one from the start that you want to do what's best for them, and that care could be a solution to make their life easier. Explain how you think a little Care could help and encourage them to think about how it could benefit them day to day - to see the positives. If at any point you find yourself becoming overwhelmed, don't be afraid to take a step back and seek advice from a professional, such as a GP. Sometimes, this insight can help people understand that they need support.

6. Be Inclusive. Everyone wants to be able to make decisions over where they will live and what kind of care they receive, so it is important to make your loved one feel as involved as possible. It can be easy to go into planning mode and want to sort everything out yourself when it comes to a loved one's care plan, but it's important that your loved one plays as much of a role in the decision-making process as possible. Feeling understood and listened to can also help to manage the feelings of losing independence and control that your loved one may be experiencing.

7. Finally, Be Positive! While care is often seen as a negative, the truth is that it can be an incredibly positive experience – and in many cases, offer people a new lease of life. Talking about some of the positives and benefits of care with your loved one may help them to develop a new perspective, and even feel excited at the prospect of what it could bring.

When it comes to fearing a loss of independence, it can also be useful to remind your loved one that care actually helps them *regain* independence. In fact, it's possible that the conversations you have could be the beginning of an exciting new chapter for your loved one.

Chapter Four – Concerns about driving

You must tell the DVLA if you have a driving licence and:

- you develop a 'notifiable' medical condition or disability
- a condition or disability has got worse since you got your licence

These conditions include, but are not limited to:

- Diabetes
- Syncope (fainting)
- Heart conditions
- Sleep Apnoea
- Epilepsy
- Strokes
- Glaucoma

With specific regard to age, there's no defined age when a person must legally stop driving. They can continue to drive into their later years as long as they can do so safely, and do not have any medical conditions that affect their driving. However, when a person turns 70, they will need to renew their driving licence with the DVLA. After that, renewal is required every 3 years.

It is the person's decision (or sometimes a GP or DVLA's decision) to stop driving. However, if you feel that their driving ability is affecting their safety, or they are putting other people in danger, then you have a responsibility to talk to them about it.

Approach the subject sensitively and tactfully. Encourage the person to think about whether they are putting themselves and others at risk - this might help them consider whether their driving is a concern.

There are some health issues can affect a person's reaction time, reflexes and other aspects of driving, such as Medication, Visual and Hearing Issues, Mobility problems, Pain or Memory issues. If the change in someone's driving ability is linked to a health condition, there *could* be a solution that would allow them to continue driving safely. Encourage the person to speak to their GP or pharmacist about any health problems or medications that may be affecting their ability to drive safely.

In addition, mobility centres offer high quality information, advice and assessments regarding mobility and driving. They have trained professionals who can assess a person's driving and look at what could help them to stay driving for longer. The aim of mobility centres is to help drivers continue driving as long as they can do so safely. Once the centre has assessed a

person's driving, they'll give advice on what to do next. That may be simply saying someone is still safe to drive or they may suggest a period of retraining to update skills and gain more confidence.

If the person agrees to stop driving, whether assessed or not, be mindful that it can be difficult for them to accept and adjust to life without a car. To help, it may be useful to research alternatives beforehand. This will allow you to offer some solutions to help the person remain independent and keep doing the things they enjoy. For example, you could find out about Public or Community transport options, timetables and routes, and whether the person would be eligible for any concessions.

Don't be fearful to have a conversation, they may be grateful that you've broached the topic with them and find comfort knowing that they have support to find a safe way forward.