

HAVING THE CARE CONVERSATION

About carers

Research from Carers UK has estimated that 3 in 5 people will become a carer at some point in their lifetime. In preparation for this, it is important to speak to your loved ones about future care and support that could be available for them. In particular, working carers, representing 1 in 7 people in the workforce according to latest research, may find having the conversation about care essential in ensuring that their loved ones receive the support they need

Who are carers in the workplace?

Employers for Carers uses the following definition to describe carers in the workplace:

Carers are employees with caring responsibilities that have an impact on their working lives. These employees are responsible for the care and support of ill, older or disabled, family members, partners, or friends who are unable to care for themselves.

About this toolkit

This Toolkit has been produced by Employers for Carers (EfC) to help you to:

- Have a conversation with your loved one about future care and support.
- Spot the signs of declining cognitive health, physical health, and emotional and social health so that you are able to have the conversation as soon as possible.
- Explore the different topics of conversation that you may need to have and why these may be particularly difficult.
- Think about how to approach the conversation about caring, increasing the likelihood of a desired outcome.

Having the care conversation

In the event of your loved ones needing care and support, or preparing for this in advance, it is helpful to speak to them to establish the care that they will need and what kind of support they want. This will not only ensure that they receive the correct care, but also that you as a carer can plan for the future and prepare for combining work with caring responsibilities.

Many people however, find it difficult to speak to their loved ones about the care that they will need. Research findings from Independent Age found that 80% of people say that the most difficult conversations to talk about are important to have. However, less than a quarter have actually had those difficult conversations. This may be because you may feel sad about the changes with your loved one and worry about the support they will need in the future. Research from Centrica Hive found that only 40% of the 40-60 year-olds they surveyed had had conversations with their loved ones about how they plan to live independently in later life. Of those who hadn't managed to hold such a conversation, 21% attributed this decision to the fact that they didn't want to upset their loved ones, and 20% said that they didn't want their loved ones to worry. You may not necessarily want all of the responsibility for your loved one or you may have your own younger family to look after. Like many families, there could be old conflicts that you feel may resurface if you bring up the conversation about care. Your loved one may also be reluctant to accept a role reversal in which they are the one who needs to be cared for. These reasons and many more contribute to avoiding the conversation about care.

For people who are not currently in a caring role, **spotting the signs** of deteriorating health could help you know when to have a conversation about care. You may want to look out for:

- Cognitive health deterioration such as forgetting things, overlooking certain things that pose a safety concern, or becoming confused.
- Physical health issues that may present such as falls, having less energy, and losing appetite. It could be that your loved one is becoming less able to carry out everyday tasks
- Social and emotional signs such as feeling isolated and lonely. They may be experiencing depression and losing interest in their hobbies.

There are some **common topics of conversation** that may arise when speaking to your loved one about their care. For example:

- Your loved one's challenging health issues, and what the future holds.
- How much money will be spent on the care and support your loved one receives.

- Every day routine tasks that they should no longer do. For example, is it safe for them to continue driving?
- Delegation of caring tasks within the family. It is important to ensure that all possible family members or friends are involved in the process so that there is not just one person that all the responsibilities fall on. This can be helped by the Jointly app developed by Carers UK, which allows you communicate and coordinate between those who share the care.

Top Ten Tips

1. Try to **find the right time** to have the conversation about care. An opportunity may present itself to encourage the start of the conversation. After the death of a friend or family member, a diagnosis or repeat hospitalisations, or a decline in health, this may provide the perfect opportunity to chat about your loved one's future care arrangements. Research from Centrica Hive found that nearly half (46%) of the 40-60 year-olds surveyed would be prompted to have a conversation with their loved one about independent living in later life by an incident relating to their wellbeing, especially one that related to their health and/or safety.
2. It is important that you **create an open and welcoming environment** to talk to your loved one. Picking an appropriate time of the day and setting for your conversation may have an impact on the outcome. Think about asking permission before you begin a conversation about care.
3. Think about **the method of your conversation**. Speaking face to face is not the only method that can be used in these tough conversations. Writing a letter or speaking over the phone may be more preferred depending on where you are in relation to your loved one and how easy it is to see them in person. It can be difficult to speak to your loved one about their care, therefore writing a letter could allow you to express your feelings in the appropriate way. You may need to keep in mind if your loved one suffers from a condition that limits their communication, or could do in the future. For example, dementia (including Alzheimer's disease) can make care conversations considerably harder. Therefore, please visit websites such as Alzheimer's UK to gain some information on the best way to communicate with someone with this condition.
4. **Be prepared** for your conversation, such as researching your loved one's condition and the possible routes of support for them. Bring this information with you so that they can read the information for themselves. It could be in the form of a needs or carers assessment, benefits that you and your loved one are both entitled to, getting support from specific charities and organisations, and looking

at home-care agencies, short-term residential care or live-in carers. You can visit our website carersuk.org, to find out more about what support you and your loved one could receive.

5. You may want to consider **who has the conversation**. There may be someone who is better suited within your family or friends circle to have the conversation with your loved one. It is more likely there will be a positive outcome if your loved one speaks to someone they trust and feel at ease with.
6. **Starting the conversation** is often the hardest part. You could share what your wishes would be if you were in their shoes first to prompt the conversation. You could also use family heirlooms or family photos to encourage them to talk about what might happen in the future. Bringing up a past or present situation that your loved one has struggled with, may be a perfect opportunity.
7. Here are some examples of **what to say** to help continue your conversation about care:
 - What can I do to support you and honour your wishes?
 - Would you like to tell me about any decisions you have made regarding your care?
 - How do you feel about being cared for/or better supported?
8. Show a **loving and warm manner**, allowing your loved one to set the pace of the conversation. It is important to listen and keep an open mind when talking about their wishes. Understand that this may be a difficult process and they may be hesitant to accept that they need support.
9. Ensure that your loved one knows they are in control of, and are as **involved as possible** in, the decision making of their future care. This could lead to more positive and open conversations.
10. If possible, try to make an **early intervention**. By spotting the signs of deteriorating health and having the conversation sooner rather than later, this means that you are able to identify problems and ensure that support can be put in place as soon as possible. This also allows time to consider all avenues for the type of support that your loved one requires. In regards to mental capacity, speaking to your loved one sooner means that they will be able to express their wishes and understand what is happening.

Top Ten Tips: Summary

1. Find the right time to have the conversation by using opportunities that have arisen naturally, such as a diagnosis or repeat hospitalisations
2. Create the right environment for the conversation to happen – thinking about the time of day, setting, and asking permission to have the conversation

3. Think about how to communicate with your loved one, whether that is face to face, over the phone, or in a letter
4. Ensure that you are prepared for the conversation. Research different types of support that may be specifically available to your loved one
5. Make sure that the right person is the one taking the lead in the conversation – someone that is trusted and likely to be listened to
6. Think about different conversation starters such as talking about your own wishes, or using a situation that they have struggled with recently
7. Prepare what you are going to say and think about how it will come across. Try to focus the conversation on what your loved one's wishes are
8. Keep an open mind and listen to their wishes. Show love and warmth towards their concerns about future care
9. Ensure that your loved one feels valued and they know they are in control of any decisions towards their care.
10. When you spot the signs of deteriorating health, try to have the conversation as soon as possible. This means that a care plan can be put in place before health issues worsen, or there is a crisis

Three next steps

1. Talk about caring with your colleagues or managers and learn about what support your employer can offer you in the workplace. Share this toolkit with your family and friends to support them with having the care conversation.
2. Tell your colleagues that your organisation is a member of EfC and that all our resources are available to them. Circulate your organisation's membership code to your colleagues so that they can access these resources.
3. Encourage your colleagues to sign up to the monthly EfC e-bulletin as people in your workplace could become carers at any time. Your colleagues can also sign up to receive the e-bulletin on the EfC website.

Contact Employers for Carers

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