



What does caring for disabled, ill or elderly people involve?

These notes accompany this free half-hour online video course that helps you explore practical aspects of providing care for family members or friends who, because of disability, illness or frailty, couldn't manage otherwise. The topics covered include:

- How much time does caregiving take?
- What might caring for a relative or friend involve?
- Why care?
- Who's involved in caring?
- Where to provide care?
- What about your own life? and
- Going forward?

It's thought that, at some point in our lives, 3 out of 5 of us will provide care for a family member or friend who, because of disability, illness or frailty, couldn't manage otherwise. In spite of this, caring is something many of us know little about unless we've had personal experience of it.

People talk about 'juggling care' and for good reason because many carers feel they're struggling to keep all the balls in the air. Ensuring that what you're doing doesn't overstretch you is important – if you have too many balls in the air, you're likely to become overwhelmed and they'll crash down around you.

This can happen when kind-hearted relatives or friends become involved in caregiving without much preparation and then struggle when it takes over large parts of their lives. Fortunately, lots can be done to improve this. Firstly though, let's consider something that, if undefined, can lead to confusion:

What's in a name – carer, caregiver or ?

There tend to be many names used to describe someone who helps a family member or friend who, because of a disability, illness or frailty couldn't manage otherwise. 'Carer' or 'caregiver' are often used and it's not unusual to add extra words such as 'informal', 'unpaid' or 'family'. For simplicity here, I call us 'carers' and refer to the people we support as our 'carees'.

Lots of people quietly get on doing what's needed to look after the people they're supporting. Especially in the early stages they might not even consider themselves as carers - they just think of themselves as 'keeping an eye on their mum', or 'helping a friend back on their feet after a serious operation'.



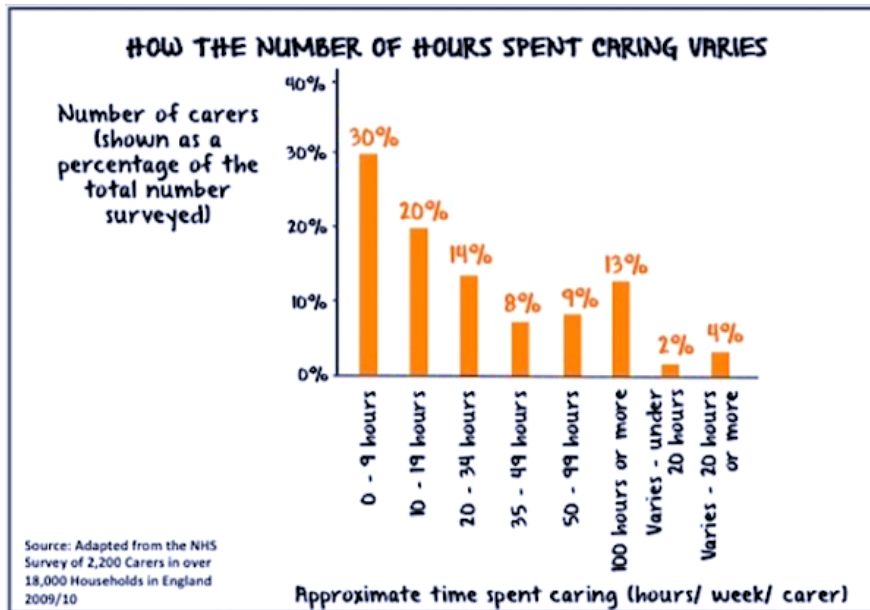
Carers are often hard to spot, so it might come as a surprise that statistics from different parts of the world indicate that, at any one time, on average one person in ten is likely to be a carer. Also, approximately 50% of carers combine unpaid caring responsibilities with employment, and over 40% of carers are male^{1,2&3}.

Some people become carers with the birth of their child or in the answering of a phone call – an accident, a sudden illness or an unexpected event that comes out of the blue, and they have little choice about their immediate response – they become carers. Others can see caring creeping up on them.

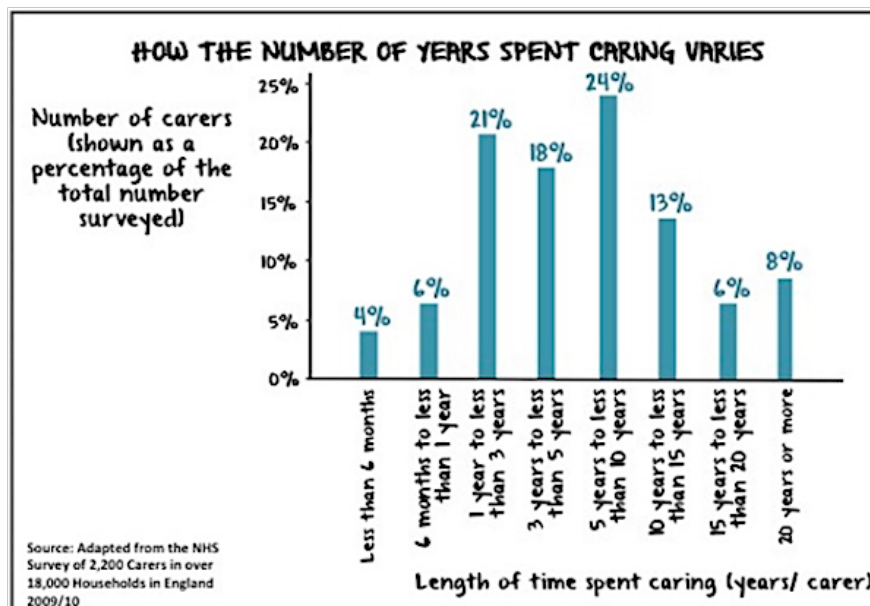
Though everyone's different and each caring situation has its own special considerations, it can benefit a person when they accept that they are a carer. They are then more likely to be aware of opportunities for receiving support and training, and can prepare themselves better for the roles they're taking on.

How much time does caregiving take?

The chart below shows the results from a survey⁴ that looked at how the number of hours per week spent caring varies from carer to carer. We can see that approximately 47% of these unpaid carers surveyed spent more than 20 hours per week caring. When you consider that many employees work around about 40 hours a week, another way of saying this is: nearly half of all unpaid carers provide more than the equivalent of 26 working weeks' worth of caregiving every year.



The survey⁴ also studied how the number of years spent caring varies from carer to carer (as shown in the following graph).



It was found that approximately:

- 9 out of 10 carers provide care for more than one year
- 7 out of 10 carers provide care for more than 3 years
- 5 out of 10 carers provide care for more than 5 years
- 1 out of 4 carers provide care for more than 10 years and
- 1 out of 12 carers provide care for more than 20 years

Most of us don't know how long we will be carers, but these two charts show that a high percentage of carers spend many hours a week providing care over very long periods of time. We need to find ways to make something we could be doing for many years be as fair and enjoyable as is practically possible. Knowing this, do you owe it to yourself (and your caree) to consider how to make the time you spend caring the best it can be? I don't say this lightly because I know first-hand how challenging caring can be, but I do believe that, when you're prepared to develop ways to help yourself in this, you'll find greater enjoyment in the everyday tasks of caregiving. With this in mind, in the next question we consider:

What might caring for a relative or friend involve?

The diagram below shows what type of care might need to be provided:



Some aspects of personal care are very intimate by nature and depending on the carer-caree relationship and financial considerations, care agencies might sometimes be brought in to provide extra support with these. If the person being supported is unable to cope with arranging these, their carer would generally deal with the smooth running of these care services and the claiming of any relevant financial benefits or allowances. Also, especially where funding is stretched, carers might become involved with campaigning for particular services or pushing for certain things to be carried out.

When thinking about what caring for a relative or friend might involve, it's important to consider How can you encourage your caree to gain or retain as much independence as is reasonably possible? It's also worth thinking about:

Why care?

Carers sometimes do things to look after their loved ones without really knowing what's best because they're not clear as to why they are helping them. This can end up with their caree getting cross and saying things like 'Go away!' and 'Stop fussing!' Perhaps worse still, if the caree doesn't put up resistance, misguided generosity on the carer's part can lead them to continually 'rescue' their loved one, even when the caree might've been able to do what was necessary. This can lead to caree's thinking they aren't capable of doing what's needed, and they then start to expect help to automatically appear. If this builds into a habit, the 'rescuer' can end up feeling overwhelmed and taken for granted. So as a carer, it's important to determine the types and levels of care really needed. By making the situation as fair as you can, and building in activities that you enjoy and value, you can use your understanding of the 'why' behind your caree's needs so as to have the levels of motivation you need for the care you're providing.

Who's involved in caring?

Before rushing to provide significant amounts of care for someone, it's worth thinking about Who might become increasingly dependent on you? By pausing to consider a person's needs sufficiently ahead, and helping them to gain or retain as much independence as is reasonably possible, it's more likely you'll be able to maintain your chosen levels of care in times of genuine need.

Who we care for will have extra challenges if our preference, in other circumstances, would have been to spend less time with them. Consider how when two people are not getting on well, a bit of time apart can normally take the pressure out of the situation. However, a carer in that same situation might not, for safety reasons, be able to walk away when their caree is 'pushing their buttons'! Instead, as a carer, you'll need to find other ways to cope, and taking time to really understand who your caree is will help you build the good relationships that lie at the heart of great care.

Also, to reduce any strains on this relationship and decrease the stress felt by you, it's important to consider - Who else cares? Gaining effective help from other people will make a great difference to how you cope as a carer, so ensure you're considering as wide a mix of people as is practically safe when thinking about Who to ask to help? Many people are willing to help – they might just need asking – along with some guidance as to what to do. By listing all the people you may need and want to provide care for (now and in the future), and thinking about who else could help, caregiving can start to become fairer and more manageable.

Where to provide care?

In thinking about where a person might live so as to receive care, it's important to weigh up their needs and expectations, along with those of their main carers and anyone else significantly involved. This diagram shows some of the possibilities:



With all these options it's important to carefully think ahead as to the likely interactions of everyone involved, as well as taking financial and legal advice where necessary.

What about your own life?

Extended periods of social distancing have understandably shut down many face-to-face options here, and whilst many online groups have rallied to provide some alternatives, everybody's lives have been affected by the changes the Coronavirus pandemic has brought to caring situations. That said, considering the following questions remains important.

When, as a carer, do you have time for yourself? Perhaps you remember how on planes, parents of young children are told that, in the event of an emergency, they must ensure they secure their own oxygen masks before putting the masks on their children. This provides a good analogy for stressing the importance of carers having enough time to take care of themselves so as to get through the tough times. Put another way:

*When carers are deprived of the oxygen of time to themselves,
their quality of life often suffocates.*

When caring for someone, understanding what motivates them increases the likelihood of their being involved in social and other activities that will increase their sense of well-being. This can then allow a carer enough of their own life to have a happier outlook, which in turn, feeds more energy into their caring situation and other aspects of their life.

Finding repeatable ways of taking breaks during your caring can help you maintain positive energy. As well as regularly having short amounts of time to yourself, if you're providing long-term care, it's good to give serious consideration as to how to have longer 'respite breaks'. The aim of a respite break is to give a carer the opportunity to totally switch off from all their caring responsibilities and in an ideal world, to do this successfully, it should be at least several days

long. Though arranging respite can initially take a fair amount of work and determination in advance, once these breaks have become an established part of what's expected, their beneficial effects are so worth the effort. Remember - caring for yourself is an important part of caring.

What's next?

It might be that what's been covered in this free course is sufficient for your needs at this time. Alternatively, you might like to visit our other online courses at www.jugglingcare.com to explore the various choices open to you going forward. With a greater understanding of potential caregiving challenges, we can take steps to build resilience and strengthen our relationships with those who may need our care, in this way increasing the likelihood of greater enjoyment in any care we provide.

Whatever you choose, I wish you the very best in all your caregiving.

Notes

1. UK Census 2011. Update: the UK Census 2021 results can be found at:
<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/bulletins/unpaidcareenglandandwales/census2021#:~:text=In%20England%20and%20Wales%20an,2011%20to%204.4%25%20in%202021>. We decided to continue using the 2011 results in the video because, as explained in the link above, with the UK Census 2021 happening in the middle of the pandemic, there were many factors that may have skewed the carer statistics results.
2. National Alliance for Caregiving (NAC) and AARP Public Policy Institute, *Caregiving in the U.S. 2015*.
3. Australian Institute of Health and Welfare 2017. *Australia's welfare 2017*. Australia's welfare series no. 13. AUS 214.
4. Adapted from the NHS Survey of 2,200 carers in over 18,000 Household in England 2009/10. Contains information from NHS Digital, licensed under the current version of the Open Government License.

Accreditations

'Heart in Hands': Copyright Annette Merrick

'Can you spot who is a carer?': Licensed from 123rf.com Rawpixel 49991452