

# Chapter Two

## Life After Diagnosis

Some family carers take up the responsibility of looking after someone who was already ill, and whose health has so deteriorated that they can no longer take care of themselves.

Many others become carers after a close relative has been diagnosed with a disabling disease, or suffered a serious accident. In this case, there is an additional emotional burden to consider. Usually, the person being cared for goes into shock. Their life is suddenly being turned upside down, and they are overwhelmed by disbelief, confusion and fear.

### They need you

As a close relative or friend, you are probably feeling exactly the same. But, as a carer, you have to pull yourself together fairly quickly, and carry on – no matter what. You need to give your loved one the strength to start their new journey, and to do so with hope and resilience. This is often easier if you encourage them to talk about their feelings and you show you understand what they are going through. Spend quality time with them, and keep your promises. If you say you will take a walk together later in the day, do it.

### A whole new life

You may need to plan ahead and organise a whole new life for the person in your care and for yourself. You may need to deal with the practicalities, such as finding specialists, obtaining medical information and dealing with financial matters. In addition, you will need to rearrange your work, family and social life around your caring responsibilities. All this while providing your loved one with the practical and emotional help they need.

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## Fighting back

Adapting to a diagnosis, new life and a new routine is a particularly delicate time. The initial sense of disbelief usually turns into sadness, and your loved one may gradually withdraw from activities and friends. You, as their carer, can make the difference between them spiralling into depression, or rising up to the challenge and fighting back. The key is to help them find new meaning and a sense of purpose in their life. The two cases studies below show how this can happen.

### Case study

'After the diagnosis, my wife gave up most of the things she used to do – no more trips to the shops, walks, visits to the church, bridge nights.

'As a husband, you can either sit there and watch, or do something to help. My wife was a nurse, so I spoke with the people at the hospital where she used to work.

'Now she does some volunteering work there, helping others with her illness, but more severely affected. She loves it. She says helping others is wonderful, because it makes her feel like she is doing something for herself, instead of giving up and hiding away.'

Michael, aged 68.

## Case study

'When Peter heard he had Parkinson's, he just took it like a death sentence. He didn't even want to take his medicines. He couldn't see the point.

'I felt so frustrated that, one day, I just snapped. "So what are we going to do?" I said. "Are we going to just cry and feel sad for the rest of our life, or are we going to do something about it, and make the most of what we have got?"

'I felt very bad for what I had just said. But, somehow, those words hit him. Since then, he started spending more and more time with our family, especially our grandchildren. Of course, he continued to have his highs and lows, but he really tried to make the most of every single day.'

Ann, aged 61.

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## Planning ahead

As reality begins to sink in, you need to consider encouraging your loved one to make arrangements for the future. This is particularly important if they have been diagnosed with dementia. Early in the course of the illness, the sufferer retains their cognitive faculties (i.e. sense, imagination, memory and understanding) and can still make their own decisions. But this will not be possible once their condition starts deteriorating.

Here are some of the things they may want to consider:

- Writing down preferences about the type of care they want to receive, should they lose the capacity to make decisions. This is called an 'Advanced Statement'. It is not legally binding but can give peace of mind.
- Deciding what medical treatments they don't want to receive in the future. This is called an 'Advanced Decision' and is legally binding.
- Claiming benefits to which they and/or you are entitled (see also chapter 3).
- Making a will. This can still be changed if your loved one wishes to do so.
- Putting their legal and financial affairs in order.