

Life as a young carer is very special. You do not ask for it and sometimes you may wish that you had never had to be a carer. You face many challenging decisions and obstacles a lot of the time, as well as situations which can be beyond your years. You often wonder why your friends don't have to visit hospitals as much as you and if they also know someone who struggles to complete daily tasks that most of us find so simple. There is no manual or guide to tell you what to do or how to feel but I believe young carers are blessed with the strength to overcome their fears and deal with their situation with dignity and grace.



I'm Rachel and I have cared for my mum for over 15 years. One of the hardest parts about caring for her is the constant feeling of helplessness; no matter what I say or do, nothing will take her pain away. This is something that I think a lot of carers feel and find difficult to come to terms with. Watching her living with chronic pain was and still is tough.

I was first aware of my mum's illnesses from about the age of five. She has a range of conditions with the most severe being degenerative disc disease. This means that her spine, particularly her lower back, is in constant excruciating pain. In the early years I remember helping out by doing small things that my mum could not do, such as keeping my room tidy, setting the table for dinner and helping my dad clear away. I did not know at the time that my mum would need me more and more as I grew up.

As a child, it was difficult to understand why she could never do the mum's race at school sports day or why she was not able to go to work like other parents. Looking back now I realise that my mum not going to work meant that I got to spend every morning and evening with her and she was always there when I came home from school – and for that I am truly grateful.

It was in 2003 that my caring responsibilities increased. That year my mum endured a spinal fusion to build up the base of her spine. I have vivid memories of going to visit her in

hospital. It was a 30 minute drive there and back for two weeks, which seemed like a lifetime. Most of the time she would be awake and chatting but other times my sister, my dad and me would just be there, watching her sleep. One visit particularly stands out for me; it was the first time she had tried to walk since her operation and she clung on to my dad as she tried to walk. I remember feeling very sorry for my mum and a huge sense of injustice — why her?

This is when my life as a carer really began. I often made dinner for the family, looked after my sister and attended to my mum's needs. As I grew up I did more and more for my family, which became a lot easier when I learnt to drive. I could go and get the food shopping, collect my mum's prescriptions and most importantly take her to any doctor's or hospital appointments that she had.

That is one thing that is still so overwhelming to me: how many medical appointments my mum needs and how much medication she takes. In my opinion, the effects of the medication my mum has to take can sometimes be just as debilitating as the illness itself. Tiredness and irritability are the two things that stand out for me.

Growing up and looking after my mum I never felt alone in what I was doing as I had support from my immediate family and close friends but I did feel some envy of others. My friends could go out with their mums whenever they wanted, whereas we had to plan to do things because of the many hospital appointments, and so on; plans which were then often cancelled due to my mum feeling too unwell to leave the house. I know that she felt guilty about letting us down but there was no need for her to feel this way; it was not her fault and after all there were always other days.

However, those responsibilities were hugely increased after she suffered a stroke in 2009. Her whole life changed and so did mine. The left hand side of her body was severely affected and she lost the use of her left hand and foot. She was unable to do much for herself and that meant I had to step in.

The stroke also left her wheelchair bound for around two years and my mum was unable to leave the house if I or another family member did not take her out.

She needed pretty much everything doing for her, from getting dressed to cooking dinner. I had to sort out her medication so that she took the correct tablets at the right time of day. Upon reflection, this was a huge responsibility for a young person but it had to be done. As well as this, someone had to be in the house with her all of the time, in case she fell or needed something urgently.

This was hard to deal with in a lot of ways because I knew that my mum wanted me to be out with my friends

or doing something other than looking after her and on occasions I probably did want to be away from the situation. However, the time that we spent together was invaluable and I'm glad I stayed in.

Leaving for university was particularly difficult as a carer. I knew that more responsibility would lie with my sister and my dad and now it was my turn to feel guilty. It was hard to remember that this was my time to leave home and enjoy all of the exciting things that were waiting for me at university. I did not just move a few towns away, I moved over 500 miles from Portsmouth to Edinburgh. I knew that I would not be around as much to care for my mum, but I came back as often as I could and my dad and sister worked out a routine between them.

Now, I'm 23 and back from university and living at home. My mum still relies heavily on my family and me to help her manage everyday tasks. Whilst I will never be able to cure any of her illnesses or take away her pain, I know that by being there to listen to her when she's down, taking care of physical needs and ultimately being a best friend to her we will continue to have the best possible life together.





It can be a challenge to find your way through the wide range of resources out there aimed at people living with chronic pain. Our online shop has a range of really useful books and audio resources, all of which have been recommended to us by healthcare professionals and/or reviewed in **Pain Matters**. Products are divided into the following convenient categories:

Managing Pain • Pain in Children Mindfulness, yoga and self-hypnosis Personal Approaches • Older Adults

www.painconcern.org.uk