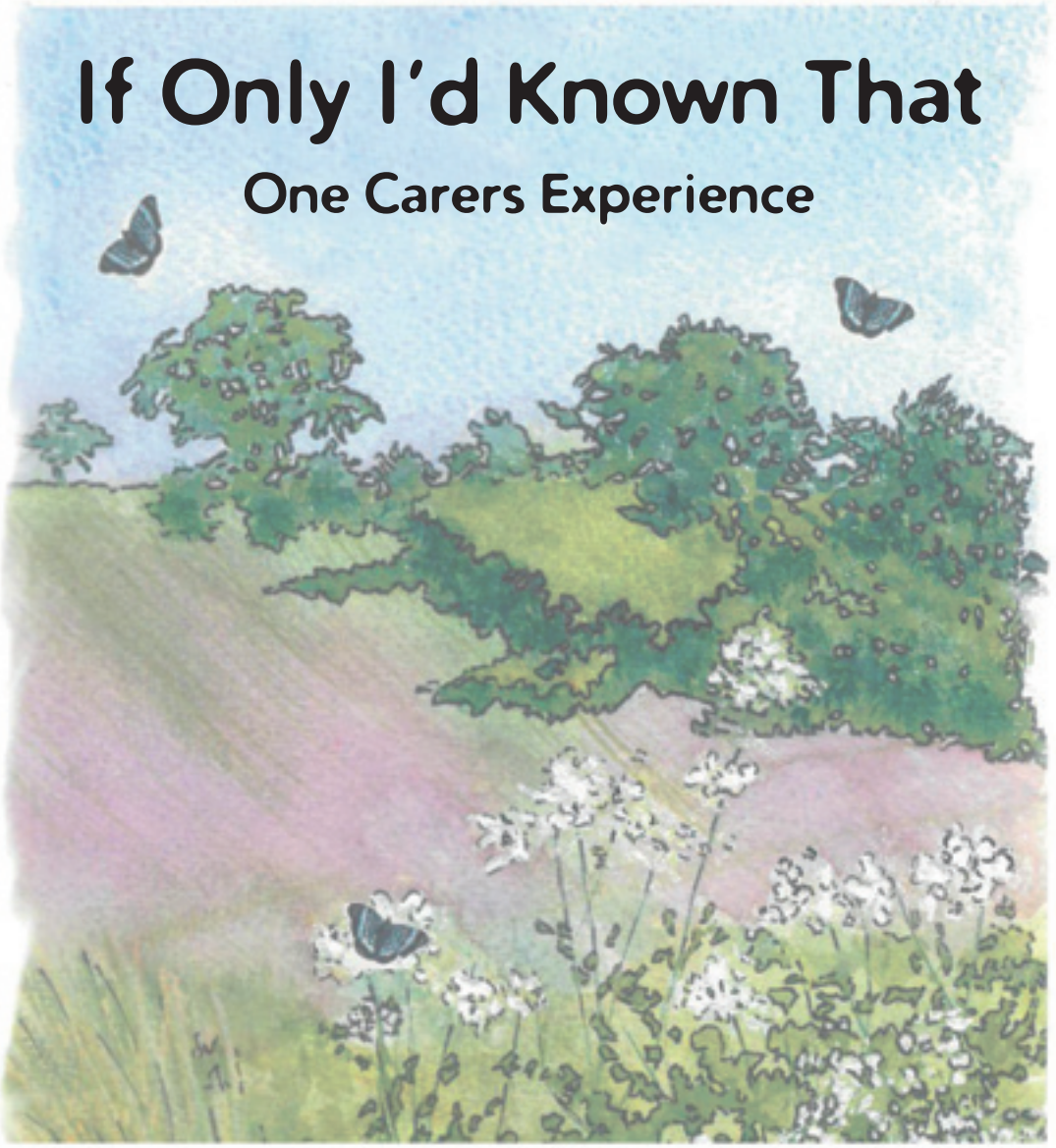
If Only I'd Known That

One Carers Experience



By Susan Hartnell-Beavis BEM

This edition edited and updated by

somerset carers

somerset carers

Who cares for the Carers? We do.

You can refer yourself or another person to Somerset Carers, just contact our friendly team.

If you regularly look after someone in a caring capacity, this may be a family member or friend, **Somerset Carers** can support you with advice and guidance.

Caring for another person is very rewarding, but can be overwhelming and lonely at times.

The **Somerset Carers** can help with:

- Linking you to groups & events in your area
- Finding information that will help you and the person you are caring for, tailored to you
- Guiding you through financial support you may be eligible for & assisting you with applications

0800 31 68 600

carers@somersetrcc.org.uk

www.somersetcarers.org

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If Only I'd Known That!

'If only I'd known that' is probably the saddest, but most frequently heard cry from Carers.

I'm sure that if all those who have ever said it, synchronised their watches and, at a predetermined time, stood in the kitchen and whispered those words, the sound of their voices would echo through the land.

I'm a past Carer, but I'm not past caring. That's why, in the hope that I might be able to save you from having to seek out the advice and information that you need, I would like to share my findings with you.

This booklet records some of my own experiences and there are a few telephone numbers and addresses of those who are there to help you - and the person you care for - lead a happier and more fulfilling life.

What is a Carer?

I can identify, exactly, the time when I became a Carer - not instead of - but as well as a loving wife. It wasn't on the morning after my husband's first stroke, when I realised that life was never going to be the same again - nor the way we had already planned to change it.

Nor was it after his second stroke a year later, when all the little advances he had made in speech and mobility were set back to a slightly worse position than they had been on the first occasion.

No, it was eight years down the line and the changes had been so subtle - and, in a way so natural - that I hadn't been aware of the effect they were having. And then I realised that things were in a mess and I needed help. It may not seem obvious, but until you have recognised yourself as a Carer - and I think the capital letter is important - there is little to be done to help you that neighbours or a tot of whisky wouldn't do just as well.

For a long time I found the neighbours worked better than the whisky! They were kind, supportive and full of encouragement and praise. Their words 'We do admire you" or "I don't know how you manage" created a sort of halo that I rather enjoyed polishing. It became a matter of pride not to let their vision of me slip, so I struggled on. I was now caring full-time for my husband who, after a series of little strokes, was suffering from multiinfarct dementia, with symptoms similar to those of Alzheimer's

Disease. If I was struggling, was I really doing the best for him, was I caring for myself enough?

It wasn't until I recognised that I was a Carer and asked for help that support became available.

Because each person's needs are different, the solutions to problems are also unique.

I spoke to my GP who referred my husband to **Adult Social Care (ASC)**. A Social Worker visited us and carried out an assessment of my husbands needs.

Somerset Carers has Carers Agents who can support and advise around your role as a Carer and what is available to you locally.

Carers Agents can refer you to ASC and Mental Health Services, as these are the only agencies that can carry out a formal Carer's Assessment.

If you think you would benefit from some help or advice in your role as a Carer please contact **Somerset Carers** advice line on **0800 31 68 600**.

If you require a formal Carer's Assessment please contact **ASC** via **Somerset Direct** on **0300 123 2224**.

In the final months and years of my husband's life, we were able to tap into a significant amount of support.

This meant my husband's life was as fulfilled as it could be and I did not need to feel guilty.

Let's Talk Money

I know it's not done in polite society, but when you're a Carer it pays to talk about money. Caring for someone can be expensive, so it's worth finding out whether you are claiming all the allowances you are entitled to.

The following are useful sources of advice

- **Citizens Advice**
- **DWP**
- **Age UK**
- **Carers UK**
- **Somerset Carers**

Carers usually try to be positive and make the best of their situation and people with support needs often find creative ways to manage.

Therefore it is advisable to get a third party to help you fill out claim forms as someone from outside can take an independent view of your situation. Organisations like **Citizens Advice** and **Age UK** are very experienced at helping with claim forms.

If the person you are caring for is 65 or over you can phone **Age UK** on **0800 678 1602** or **Citizens Advice Bureau (CAB)** will advise for any age.

It is important to remember that your circumstances may change. The person you care for may start with the lower rate of Attendance Allowance (AA) **or** Disability Living Allowance / Personal Independence Payment (PIP). If their needs increase you can apply for a review of their rate of payment.

Physical disabilities may be so severe that you need to adapt a room of your house specifically for the use of the cared-for person - or add an extra bathroom or kitchen. You may be entitled to a grant for these alterations, speak to Somerset Direct or your local District Council.

You may also be entitled to a reduction in your Council Tax, contact your District Council for advice on eligibility and how to apply for this.

If someone in your household is on Pension Credit you may be entitled to a discount on your water bill. Contact your water provider for information on eligibility and how to apply.

Somerset Carers can advise you further on applying for these discounts.

Another thing you should discuss is Lasting Power of Attorney. This is particularly important if there is a likelihood of a decline in mental ability in the future, but really should be considered by us all. It is important to consider this early as the person granting the Power of

Attorney must fully understand the implications at the time they sign the forms.

None of us knows what the future holds and this is a way of ensuring our own wishes are taken into account, both financially and personally (e.g. what type of care you would like to receive, whether you want to stay in your own home if at all possible) if we become unable to make our own decisions.

Those who have granted Enduring Power of Attorney under the previous legislation do not need to alter these arrangements. However, if you want to extend the power given to include health/welfare decisions, then this can be done.

It is important to take good quality advice on this complex issue, for example from Citizens Advice or a Solicitor. You can find more information on the government website **www.gov.uk** and go to the Office of the Public Guardian section.

Continence

All Carers are like camels. No! It's not that they always have the hump, it's just that there's always one last straw that breaks them.

Mine was incontinence. There, I've said it- and I feel as naughty as if I'd said knickers in front of you all!

Incontinence has all sorts of causes and not all of them have to do with loss of control. Urinary infections can be one trigger and this may also cause a temporary decline in understanding/mental ability. You should always check with the GP, especially if the problem comes on suddenly.

Other causes of incontinence may be, forgetting where the toilet is, not knowing what to do when you get there, getting there too late, help too slow in arriving. Sometimes the amount of warning people get before they need the toilet becomes very short, or they can no longer interpret the signals their body gives them.

A regular plan of drinking plenty and going to the toilet every couple of hours can really help.

If the problem becomes ongoing the GP can refer you to the NHS continence service for an assessment and pads may be provided.

Sharing the Caring

- **Do you ever feel you've done ten rounds in a boxing ring when you've finished getting the person you care for up in the morning?**
- **Do you ever wonder what it would feel like to go to bed just tired enough to sleep - not so exhausted that you lie awake for hours?**
- **Do you ever wonder why it's your neighbours who get all the winning smiles, while you just get the snaps?**
- **Do you ever feel like giving up?**

Well don't, because there's help at hand!

Most people who care for someone feel guilty if they wish they could have a break from their duties for a while. But have you ever thought about it the other way round? If the person you care for is at home, with only you for company, maybe they'd like a break!

It wasn't that, after more than thirty years of marriage, there was nothing more for us to say to one another - we still had a very good relationship. But when dementia sets in, then the person who has to answer the same questions hour after hour, day after day, week after week, month after month - and sometimes year after year - is not

always ready with a fresh answer or a merry quip!
The fact that I had a few hours to myself was a bonus.
In the early days I really do think the major beneficiary was my husband. But as time went on, and the problems increased, the balance changed. However willingly you care for someone, there comes a time when stress and loss of sleep sap your own resources and your own health can be in danger. And if ***you*** fall ill, who's going to do the caring?

Respite can come in different forms and it is important to think as widely as you can.

- Could a family member come to stay while you go away, **or** could the cared for person go to stay with family for a few days to give you a break at home?

- Does the person really need a Carer present around the clock, what are the risky points in their day and how could these be made safer.

- Perhaps some extra care or technology at home would help and be less disruptive - could you consider using a Micro-Provider?

Somerset Carers can help you think creatively about how best to go about getting a break.

THANK GOODNESS I KNEW THAT!

This Could Be You!

- **Wanting a break?**
- **Not sure if you're eligible for help?**
- **Need someone to talk to?**
- **Often feel isolated or lonely?**
- **Would like to know what help is available?**
- **Feel worried about the future?**

If you've answered "yes" to any of those questions, then it's time to contact **Somerset Carers** on **0800 31 68 600** who will arrange for a member of the team to contact you.

Carers can be very undemanding people and we don't always like to ask for help. You may not even be sure that there is any help out there for you, but until you ask you don't know.

Did you know that you can contact **Somerset Carers**, **Adult Social Care** and the Practice Nurse at your surgery without going through the GP?

Somerset Carers can provide information about what is available in your community to support you as a Carer.

Most areas have Carers Groups where Carers can share their experiences and even have fun!

Within your GP surgery there may be a Carers Champion who is there to ensure Carers have access to information about the support that is available. Make contact today and get yourself put on the Carers Register at your surgery.

If there isn't a specific Carers group available, think about joining a more generic social group such as a book club or a class. There will probably be other Carers at these who wouldn't have thought of joining a specific Carers group.

IF ONLY I'D KNOWN THAT!

My Husband's Cake Walk!

An aspect of caring for someone that can be challenging is if they have mobility issues.

In my case, caring for my husband, it was dementia's influence on his mobility. Dementia can play funny tricks on the brain. It can sometimes tell a chap that his legs won't work, or that he can't put his feet out of the car, or that he can't walk through a doorway. No use anyone saying "Nonsense, of course you can!", would you believe what someone else said, or would you believe what your own brain told you?

But if the brain learns that there's chocolate cake for tea, and it knows that tea is being served in the sitting room, then it had better find a way of getting there - fast! And if the quickest way to get there is to stand up and walk, then that's what it will arrange. Don't ask me how it does it, but it does. It works well with toasted teacakes, too, and I'm sure if you were to try it you would have success with a nice lemon sponge.

But of course there are times when even these strategies won't work and more physical help is needed.

If the person you care for has fallen, been unwell recently or struggling to get around the house safely you can contact your GP who may be able to refer you to the local NHS rehabilitation team. They may be able to offer you

options such as an exercise plan or some equipment. The British Red Cross have aids and equipment that you can rent at low cost. Their telephone number is **0808 196 3651.**

If mobility outside the house is a problem, the Blue Badge scheme may provide extra help. Shopping or going to the dentist can be made easier if you can park right outside, or within a few yards of where you want to go. Contact:

bluebadge@somerset.gov.uk
www.somerset.gov.uk
0300 123 2224 (Somerset Direct)

You may feel that some training would help you in your caring role. Somerset Carers have details of free training for Carers on their website:

www.somersetcarers.org

One aid that I learned about too late, but which would have been very useful, is the car passenger swivel seat. It can be fitted to almost any make of car and swings right out to make it easier for someone with limited mobility or flexibility to sit down before getting into the car. I'm sure one of those would have solved another of our problems. Another thing that is now available, and which is rather less expensive, is a swivel cushion, but an even cheaper option, which works wonderfully well, is a plastic carrier bag placed on the seat. Try it. You'll be surprised!

NOW IF ONLY I'D KNOWN THAT!

The Language of Love

Sometimes one of the most distressing problems a Carer has to face is when normal conversation becomes difficult.

When we were first married, my husband and I hardly needed to speak to understand one another. We were so in tune that we used a sort of shorthand, supplemented by smiles and laughter.

The deterioration in his language skills was gradual, with the occasional step change. Towards the end it was his ability to understand our shorthand that was lost. Unless things were said with absolute simplicity and clarity they meant nothing to him. It was useless for me to say "But you know what I mean" because he didn't.

But his mind was still very active. Luckily he retained his sense of humour (which is not always the case!) and his quick wit often showed through in the puns he could produce with amazing speed and regularity. This gave me an idea.

We had moved from Scotland 10 days before my husband's first stroke, which meant he had no local 'scientific' friends, so I asked the Institute of Physics whether they knew any retired members who lived locally and who would be willing to come and talk with us over lunch or tea.

They sent out letters to several members with postcodes close to ours and within a few days the first reply came - though the writer pointed out that he was 92 and nearly blind! Undaunted, we invited him and his wife for lunch.

From the moment they arrived we knew it was going to be a success. By the end of their visit we felt we had always known one another and my husband's ability to join in had been exactly as I had hoped.

In the end six members had the courage to take up the challenge of re-engaging my husband in normal life and our social calendar became very full, with great benefits to both sides.

This taught me that we sometimes have to find unusual ways to solve problems.

In my experience people really do want to help, but don't know what they can do. If invited they often respond willingly.

The purpose of this chapter, therefore, is to encourage you to seek out help, whether from professionals, volunteers, family or friends and sometimes even strangers. With their support, life for you and the person you care for can be made less stressful and more rewarding.

IF ONLY YOU CAN REMEMBER THAT!

Notes

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For more organisations that may assist you go to:

www.somersetcarers.org

Who Can Help You

Local and National Organisations

Quick Reference Contacts

Somerset Carers	0800 31 68 600
Community Council for Somerset (CCS) Village Agents	01823 331 222 https://somersetagents.org/
AGE UK	0800 6781602 National 01823 345613 Somerset
British Red Cross	0808 196 3651
Carers UK	0808 808 7777
Carers Trust	0300 772 9600
Citizens Advice	0800 144 8848 National 0808 278 7842 Somerset
NHS Somerset Carer Service	01749 836606
Open Mental Health (OMH) Mindline	01823 276892 or 0800 138 1692
Somerset Direct (Somerset Council services including Adult Social Care)	0300 123 2224

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