



If Only I'd Known That

One Carer's Experience

With helpful advice for Carers in Dorset

Acknowledgements

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Donna Blanche and Emily Stafford
Sue Warr and Carol Davies

The Leonardo Trust
PramaLife

Cover art: Jo March Art

07425 133175

01822 2581645

jomarchwillet@gmail.com

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Please note: The following is one Carer's account of their experiences. Services, policies, and benefits mentioned are subject to change. Therefore, the current situation may not be the same as reflected in this booklet.

Please always refer to **CRISP Carers Support Service on 01202 128787** for Bournemouth, Christchurch & Poole Council or **Carer Support Dorset on 0800 368 8349** for Dorset Council for up to date advice.

To obtain further copies of this free guide please contact The Leonardo Trust 01202 698325, info@leonardotrust.org or PramaLife 01202 207329, info@pramalife.org



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ALERT

After you have read this booklet and can identify yourself as a carer, we strongly advise that you:

1. Register with the GP of the person you care for as their Carer and register with your own GP as a Carer (if at different practices). This will entitle you to free flu jabs, more convenient appointment times and access to the 'Carers Champion' that many GP Practices have. It will also give you access to other useful information and support.
2. Contact **CRISP** (BCP Council) **01202 128787** or **Carers Support Dorset** (Dorset Council) **0800 368 8349**. They will give you advice and information, support, courses to help you care and access to an emergency back-up scheme (Carers in Crisis), social events, a discount card and more.

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 like a scream.

I am a 'Past Carer' but I am not past caring. That is why I'd like to make the title of this book so unnecessary that future Carers would scratch their heads and say they could think of no circumstances in which it would need to be read.

In the hope that I might be able to save you from having to seek out the advice and information that you need in your task I would like to share my findings with you. This booklet records some of my own experiences, as well as providing you with a contact list of numbers of those who are there to help you – and the person you care for – lead a happier and more fulfilling life.

Susan Hartnell-Beavis

What is a Carer?



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 was not 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 had not 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 I recognised myself as a Carer (and I think the capital is important in this context) there is little to be done to help you that neighbours or a tot of whisky would not 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.

But just a minute. Who was I caring for? It was my husband who, after a series of little strokes, was suffering from multi-infarct dementia, with symptoms similar to those of Alzheimer's Disease

If I was struggling, was I really doing the best for him? I may have been wearing the halo, but was he the martyr to my cause?

“It was not until I recognised that I was a Carer that we were measured up and fitted with the full range of support that was available”.

My moment of truth came when we were on holiday in Scotland and I phoned my GP from there and cried, “HELP”!

On our return he arranged for a visit from someone who came as a Carers Case Worker and left as our friend. I do not think I am being unfair to her if I say that we learned a lot together. Because each person’s needs are different the solutions to problems are also unique. She, figuratively speaking, took out her tape measure and ran it over the two of us. She made it clear that her reason for being there was to produce a package that would suit us both and give

my husband **and** me a better quality of life.

By the time my husband died I think we had tapped into well over 75% of the resources that were available to us. This meant that the last year of my husband’s life was as fulfilled and dignified as it was possible for it to be and I can look back on it with a great sense of joy and gratitude.

If you think you could be helped in your role as a Carer and if the person you care for lives in Bournemouth, Christchurch or Poole, phone **CRISP Carers Support Service on 01202 128787** or if you come under Dorset Council, then phone **Carer Support Dorset on 0800 368 8349** and ask for a referral for a Carers Assessment.



Let's Talk Money

Let's Talk Money

I know it is not done in polite circles but when you are a Carer it pays to talk about money. There are a hundred and one ways (and those are only the ones I know about) that caring for someone can be expensive so it's worth finding out, as soon as possible, whether you are claiming all the allowances to which you are entitled.

Attendance Allowance is for those aged 65 or over and is non-means tested. **Personal Independence Payment (PIP)** is for the under 65's. These are like the keys to a Chinese puzzle. If you are successfully assessed for these then there may be other benefits you can access.

Mind you, they do not make it easy. The forms are thick and the questions, though written in normal, everyday language, are quite difficult to answer, but do not despair! There is always help at hand you can always contact the **Leonardo Trust on 01202 698325** for support.

One of the problems is that you do not want to be disloyal to the person for whom the allowance is being claimed. This is especially true if it is someone you love, as well as care for. For that reason, it is a good thing to get help from a third party. The Leonardo Trust and the Department of Works and Pensions will help, as will Citizens Advice.

Ask for advice on the benefits for which you qualify.

Do not assume that the assessment of your needs is done only once. It is important to remember that your circumstances may change. You may start with the lower rate of **Attendance Allowance** or **Personal Independence Payment** because care is provided only during the day or the night. If it becomes day **and** night, a claim can be made for a higher rate.

If you are under 65 (or 60 for women) and spend at least 35 hours a week caring for someone and the person for whom you are caring for is eligible for **Attendance Allowance** or **Personal Independence Payment (middle or high rate)** then you may be able to claim **Carers' Allowance**.

Moreover, if you have been paying National Insurance contributions in your own right these may, in some circumstances, continue to be paid if you are entitled to **Carers' Allowance**. This means that you will have no gaps in your contributions, which is important for your own future pension. It is always worth claiming these benefits, even after the age of 60. They are unlikely to be paid but they may entitle you to claim other things like **Council Tax Benefit, Housing Benefit or Pension Credit**. This is called an **Underlying Entitlement**.

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. You may also be entitled to have your house put into the band below your present assessment for Council Tax.

Severe mental impairment is yet another criterion for re-assessment of Council Tax. Ask for forms from your local Council Offices *and* liaise with your GP who must certify that the medical conditions are met. You could also apply directly to the **Leonardo Trust** whose advice and funding supports carers in a variety of ways.

I'm not an expert on benefits and can only tell you what I learned from my own experience. There is a lot of financial help available; my advice is always to ask. Contact, Carer Support Dorset, the Job Centre or Citizens Advice. Don't leave it too late or you'll be saying those dreaded words:

"IF ONLY I'D KNOWN THAT!"

Another thing that we should discuss is **Lasting Power of Attorney**. This is particularly important if there is the possibility of mental impairment in the future, but really should be considered by us all. None of us knows what the future holds, and this is a way of ensuring that our own wishes are considered, both financially and personally (e.g. what type of care you wish to receive) should you become unable to make your own decisions through incapacity.

Those who have already granted Lasting Power of Attorney to their chosen trustee do not need to alter these arrangements unless they want to extend the powers, beyond financial arrangements, to their personal care. The Leonardo Trust or Citizens' Advice (CA) can help you with this or you can speak with your solicitor.

It is important to consider this early because the person who is granting the power of attorney must be fully capable of understanding what is being done at the time of signing the forms. It cannot be done when mental capacity has already been lost and there are serious implications about who makes the financial and personal decisions for people who have not made this arrangement. If the person you care for becomes terminally ill it is worth remembering that, if he/she has not been seen by a doctor after death, or during the 14 days preceding death, the coroner must be informed.

Unfortunately, the police will probably become involved too. This does not mean there are suspicious circumstances, but it may mean that the body will be removed from your care. If you can arrange regular visits from your GP – or if your GP records that death may be imminent so that the Out of Hours Services know that there are unlikely to be suspicious circumstances if the death occurs during their watch - it should be possible to avoid this. Difficulties like this are most likely to arise at the weekend.

These are occasions when it could be too late to say:

“IF ONLY I’D KNOWN THAT!”



The Big Taboo

The Big Taboo

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

Mine was incontinence. There, I have said it – and I feel as naughty as if I had said *knickers* in front of you all! Silly isn't it? But it is all those years of potty training, I suppose. First our own, then our children's and then, a step removed, perhaps our grandchildren's. We have been conditioned to feel that it is all a matter of self-control – and none of us likes to lose that. I had tried to shut my eyes and my mind to it, but it would not go away. I took all the precautions I could to avoid the problem and to hide the consequences if that did not work. The drain on my emotional resources, especially when we were away from home, was enormous.

Incontinence has all sorts of causes – and not all of them have to do with loss of control.

Urinary infections can be one trigger. This may cause a change in behaviour, so it is always a good idea to check this out with your GP, especially if it is a sudden-onset problem. But, have you ever thought what it must be like to know that you want to go to the toilet but are not physically capable of getting there in time? Or if you get there the seat is too low for you to sit on? Or if you have got down there, there's no way you can get back up again? Or if your brain is giving your legs the wrong messages (as it does sometimes with people who have Parkinson's Disease or similar symptoms) and you can't turn around to sit?

If the person you care for has challenges like this, contact **Care Direct on 01202 454979** (if the person you care for lives in Bournemouth) or the Christchurch **Helpdesk on 01202 633902**. If the person you care for lives in Poole or Dorset, then phone **Dorset Direct on 01305 221016** for Dorset Council and ask for an Occupational Therapy assessment and discuss with your GP. The solution may be as simple as fitting a raised seat or rails.

Of course, there are other reasons for incontinence that **do** have their basis in loss of control, but even these can sometimes be cured. Most modern mothers will have been taught pelvic floor exercises after the birth of their children, but these can be just as useful for those who have slight urinary incontinence, whether they have had children or not. It's sad to think of the number of people who hide this problem because they are ashamed – and it's not just a

problem that affects the elderly when a simple daily exercise might be all that is required. *In fact, I am doing mine now, while I type!*

If none of the above solutions fits your problem, there are several different options, continence pads being one of them. This may be an acceptable and convenient method, but for some it will mark, not just the loss of control, but a loss of dignity too. But all is **not** lost. Have you ever heard of a non-invasive catheter or sheath? No? Nor had I, but it transformed my husband's life – and mine.

Again, I am not an expert, but I found a lady who was our local Continence Adviser and she approached her subject with a delicate enthusiasm that removed all embarrassment. Contact your GP and ask for a continence assessment.

Just think what solving this problem could mean to you and to the person for whom you are caring. No more watching like a hawk for signs of discomfort. No more refusals of invitations because there might be an accident. Less washing. Less cleaning up. Less bad temper and tension between you both. Now.....

**“IF ONLY YOU’D KNOWN
THAT!”**



Time for a Break

Time for a Break

*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 it might be the other way around? If the person you care for is at home with only you for company maybe **they would like a break!***

When it was suggested that my husband should be assessed for a place at a Day Care Centre, I felt dreadful. On the morning that I took him for the first time I wept. My sense of having betrayed him was such that I thought he would never forgive me.

Imagine my surprise when the volunteer driver who brought him home delivered a happier, livelier and more talkative man than I had known for some time. For three days a week he was with a group of people who knew how to stimulate him both mentally and physically.

It was not that after more than thirty years of marriage there was nothing more for us to say to one another – we still had an incredibly 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. How wonderful to have a new audience, especially if you enjoy a good chat. 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 is going to do the caring?**

Since I stopped caring there is a service called “**Carers in Crisis**” which is available for carers looking after someone in **Bournemouth, Christchurch or Poole**. This service provides free care during the initial 48-hour period if due to an emergency you are not able to provide the usual care. To access this service, you will need to have had a carers’ assessment by someone in Adult Social Care and be registered with the scheme. This service is available 24 hours a day, 365 days of the year. After the 48-hour period the person you are caring for may need to purchase their own care depending on their financial circumstances.

Alternatively, if you live elsewhere in the **County of Dorset** a one-stop service called “**Carer Support Dorset**” aimed at providing vital access for carers to information, support, training and respite. They can be reached on **0800 368 8349** or **admin@carersupportdorset.co.uk**

You can also access information and make a referral via **www.carersupportdorset.co.uk**

If an emergency caring situation occurs, then contact **Adult Social Care on:**
Office hours: 01305 221016
Out of hours: 01202 657279

Carers Direct NHS is a national helpline where carers can find out about a variety of support services including benefit entitlements and carers rights. The helpline is open 9am - 8pm Monday to Friday 11am - 4pm Weekends. Calls are free from landlines and mobiles within the UK. The number to call is 0300 123 1055. Alternatively, you can use their website to book a free call-back at a time that suits you or submit an online enquiry form or even join the web-chat service. The call back can be made in over 170 different languages.

There is a wide range of useful information that can be found on the website at www.nhs.uk/carersdirect.

This is the time to start talking about **Planned Respite Care** and it is worth asking about it **before** you think you really need it. There are two reasons for this; if you leave it until you reach crisis point it may not be possible to arrange at short notice – and if you have short breaks from your caring you may delay the crisis. It is amazing how a few days without the strains of looking after someone can re-charge the batteries.

Although these short periods of respite do not infringe the rules for claiming Attendance Allowance they **must** be reported to the Benefits Agency. The first experience of respite is not always a happy one. It can be a bit like sending your child away to boarding school, although of course your loved one is not a child. For you there is an underlying sense of loss and guilt and you might be concerned that for the one in

care there is possibly a feeling of rejection and abandonment. But, just as most children soon settle down at school and only pull at our heart strings while we are looking, so most people who go into Respite Care soon feel at home in a safe and loving environment.

If it is possible for respite to be provided in the same place each time it becomes less traumatic. The cared-for person will know the staff and they will know him or her. That is a great benefit to both sides. I can never thank enough the professionals who helped to give my husband and me a better quality of life during his last nine months.

**“THANK GOODNESS
I KNEW THAT!”**

Sharing the Caring

- Do you ever feel you have done ten rounds with Frank Bruno when you have finished getting the person you care for up in the morning?
- Do you ever wonder what it would feel like to go to bed only tired enough to sleep – not so exhausted that you lie awake for hours?
- Do you ever wonder why it is your neighbours who get all the winning smiles, while you just get the snaps?
- Do you ever feel like giving up?

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

You know the old saying, "You always hurt the one you love"? Well, when someone is afflicted by dementia, whatever the cause, this may become literally true.

It is not intentional, and quite often comes about because the person concerned is unaware of his or her own strength. But there is also an element of not needing to be as inhibited in one's behaviour with someone you love or know very well. You **could** take it as a compliment!

Of course, dementia is not the only reason why there may be a problem. It may be physical disabilities that make things difficult. Perhaps cooking lunch is beyond the person's capabilities – or doing the shopping or the cleaning. Whatever the situation, there is a caring cavalry ready to ride in. They are called **Home Care Workers**.

Local Services can make an assessment of your needs, work out a package of care to suit you, or arrange with private agencies to supply the help. This is not a free service, but it is charged on a means tested basis. Bearing in mind that the person being cared for is probably getting **Attendance Allowance** – that is paid to help provide care – then the charges should not be unreasonable.

Direct Payments are local council payments available for anyone who has been assessed as needing help. The payment could be a lump sum towards a break, or a piece of equipment to sustain the carer.

Some people may have a regular payment to employ a Personal Assistant, to help with personal care or to help them access activities. They are normally available if you are a carer aged 16 or over, or a parent (including people with parental responsibility for a disabled child).

Once again, to find out what may be available, contact, **Care Direct on 01202 458204** if the person you care for lives in Bournemouth or Christchurch, or the **Helpdesk on 01202 633902** if the person you care for lives in Poole, or **Dorset Direct on 01305 221016** for Dorset Council.

Our **Care Workers** had all sorts of strategies for dealing with someone whose brain could not always process messages correctly. “Time to get up,” wasn’t necessarily followed by appropriate action, but “Race you to the bathroom!” produced an immediate response. “Shall we go through to the bedroom?” was an invitation often refused, but “Didn’t someone give you a lovely new painting of a ship”? resulted in jumping up to give a delighted exhibition. It was a sort of “Take me to see your etchings” approach!

If legs had forgotten how to tuck themselves under the bedclothes in English, why not try German – a language my husband had learned at university in Munich? And if things do not go quite according to plan – laugh. I heard fits of giggling coming from the bedroom one evening and saw my husband in bed, with one of his angels on top, legs and arms in all directions. She had, apparently, slipped on the floor. “It wouldn’t have been so bad,” she said afterwards, “If he hadn’t said, Oh I did enjoy that!” These Care Workers were often the ones to get the praise, but they deserved it, for they did everything with care. They were part of our family for nine months and we shared lots of ups and downs.

This could be you!

- Wanting a break?
- Not sure if you are 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 **CRISP Carers Support Service on 01202 128787** if the person you care for lives in Bournemouth, Christchurch or Poole, or **Carer Support Dorset on 0800 368 8349** for the Dorset Council area for Dorset Council. They are available to help you specifically.

Carers can be very undemanding people and often do not realise they are a Carer. They don’t like to bother their GPs and don’t know they can contact Adult Social Care or Community Nurses without going through their doctor. They aren’t even sure there’s anything that can be done anyway, because they’ve never met anyone with problems quite like theirs.

Care Direct and Adult Social Services can provide information about all the services that are available through **Care in the Community**. They can suggest ways of getting a break from caring, perhaps helping to plan holidays for the Carer and Cared-for. They can put you in touch with your local Carers Support Group or refer you to **The Carers Trust**, which has free online courses about caring for someone with dementia or **The Recovery Education Centre** who provide free training courses if you are caring for someone with mental health issues. The courses are mainly held out in the community, so you should not have to travel too far to attend.

If you want information about **Opticians, Dentists and Chiropodists** who are willing to do home visits, contact **Care Direct on 01202 454979** if you live in the Bournemouth, Poole & Christchurch Council area or **Dorset Direct on 01305 221016** for the Dorset Council area.

Make contact today, and you should never again have to say:

“If ONLY I’D KNOWN THAT”

My Husband's Cake Walk!



My Husband's Cake Walk!

There was a jolly piece of music from the 1920's by Debussy from which I've taken a liberty with the title of this chapter. But you still do not know what I'm talking about, do you?

It is **MOBILITY**, and if you do not see what that's got to do with cake, I'd better explain.

Dementia can play funny tricks on the brain. It can sometimes tell a chap that his legs will not 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 is what it will arrange.

Do not ask me how it does it, but it does. It works well with toasted teacakes too, and I am sure if you were to try it you would have success with Dundee cake or a nice lemon sponge.

But of course, there are times when even these strategies will not work, and more physical help is needed. You may need to access training to help you with this. Contact either; **The Carers Trust** or **Oakley Friends** who offer free training in First Aid, Continence Advice, Safer Handling, Stress Management, Falls Prevention and Ways to cope with Memory Loss. For information on future courses contact Judy at **Oakley Friends on 01202 021705**.

Contact Dorset Direct on 01305 221016 or Care Direct on 01202 454979 or contact your GP and ask for an Occupational Therapist to come and assess the needs of the person for whom you care and arrange for suitable help to be provided. This may mean having rails fitted through the house to give support and confidence; it may mean a walking stick or a Zimmer frame – or it may mean a wheelchair. These can all be supplied and increase independence, which is so vital.

The **British Red Cross** can also lend a variety of aids designed to help you. If climbing the stairs becomes difficult, then you may be able to get a grant to have a stair lift fitted, which maintains normality, especially for those who are used to going upstairs to bed.

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 **Dorset Direct on 01305 221016 or Care Direct on 01202 454979** if the person you care for lives in Bournemouth or Christchurch. Or try the **Helpdesk on 01202 633902** if the person you care for lives in Poole. They will be able to help you to assess the capabilities of the person for whom you are applying and fill in the form over the phone.

I filled in my husband's form as honestly as I could, stating that he could walk about a quarter of a mile. "Yes, but how long does it take?" my GP asked, reminding me that there is no shame in asking for help. Remember, though, the Blue Badge is for the disabled person, not the chauffeur, so you can't park anywhere, leaving your charge sitting in the passenger seat while you go off to have your hair cut! If you do, be prepared for a £1000 fine.

One aid, that I learned about too late, but which would have been particularly 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 am sure one of those would have solved another of our problems.

"NOW, IF ONLY I'D KNOWN THAT!"

The Language of Love



The Language of Love

Sometimes one of the most distressing problems a Carer must face is when normal conversation becomes difficult. Direct questions seem to erect a barrier within the brain, which makes answering embarrassingly slow and perhaps even impossible. But if there are two or three people talking - and the subject interests the person you are caring for – it can produce surprising results. It is as though, when the brain is not being put under pressure, it is free to respond.

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. It was, I suppose, the Language of Love.

The deterioration in his language skills was gradual, with the occasional step change when he suffered an ischaemic

attack. Towards the end it was this ability to understand our shorthand that was lost. Unless things were said with textbook use of syntax and grammar, they meant nothing to him. It was useless for me to say, "But you **know** what I mean", because he did not. Where once we had used so few words to express so much, now we used many words to explain the simplest things.

But his mind was still highly 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. It was this "inspirational" speech that 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.

This taught me two lessons. The first is that we sometimes have to find unusual ways to solve problems. Secondly, we Carers often do not like to ask for help, assuming that friends and neighbours will be too embarrassed by the changes that are taking place. However, in my experience, people really do want to help but do not know what they can do. If invited, they respond willingly, and feel privileged to be involved. 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.

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!”

Supporting someone with Memory Problems



A Carers Guide ~ How to recognise and support someone with Memory Problems

Do you go into your room and wonder why you came in? Did you forget where you put something? Sound familiar?

Do not worry – this happens to us all, particularly Carers - It is normal for our memory to let us down sometimes, particularly when we are tired, stressed or just have too much going on.

But - Dementia is different - so what is it?

Dementia describes a group of diseases that affect the brain. It changes normal brain function. The effects on behaviour depend on which area is affected and which type of dementia is involved.

Dementia can affect:

- **Memory:** Hard to keep hold of new information
- **The Thinking Process:** difficulty putting thoughts in order and losing the plot
- **Communication:** difficulty understanding speech or reading body language
- **Functioning:** problems with day to day living.

Things you may notice: -

- **Loss of memory:** increased forgetfulness, unable to remember names, places, or appointments, losing things more often, repeating phrases or asking the same questions.
- **Mood changes:** people with dementia can feel frightened or confused particularly at night.
- **Communication problems:** an ongoing decline in all forms of communication like talking or writing.

The failing brain could be compared to an old computer unable to store any new files (information) but, the old information they have stored away as memories is still there. A person may not remember what happened yesterday – but can remember quite clearly what happened years back.

*A person with memory problems may feel:
Frustrated... Angry... Upset...
Distressed... Alone... Frightened.
It makes day to day life difficult
for them and all those involved
in caring for them.*

If you suspect a problem what can you do?

Early diagnosis of a dementia can help in the management of symptoms.

- Report your concerns to your GP, you may find others have noticed changes. Keep a diary of incidents and concerns.
- Your GP will do a physical examination, as there can be many other causes which affect memory other than

dementia such as infections, depression etc.

- If all other problems have been ruled out, your GP may consider further assessment by a specialist.
- It can take some time to get a diagnosis. Do not be afraid to go back to the GP if the problem is not confirmed first time.
- There are treatments that can slow the rate of decline and lots of help and advice.

Top tips on how to help

- Give a person space & time to talk, do not speak for them and encourage independence.
- Do not argue or correct; they may not feel they are doing/saying anything wrong.
- Distract them; maybe with an activity they have always enjoyed. Talk about things they did or liked in the past.
- Do not over stimulate; keep any background music/noise to a minimum.
- Ensure there is good light, no dark shadows.

- If they are sad allow them to express their feelings but encourage and praise them.
- Keep questions simple; 'let's have a cup of tea' reduces demands but is not such a confusing question as 'would you like tea, coffee or chocolate' or 'would you like it now or later'?

Important: If you as the Carer feel angry or stressed leave the room for a short break.

Promoting Good Nutrition



Promoting Good Nutrition

An Information Guide on how to build yourself up and reduce the risks of malnutrition.

Carers often report difficulty feeding the person they care for; lack of mobility and general ill health may cause people to lose interest in eating. Carers also may find themselves being too tired to cook a proper meal.

To stay well we need the right fuel.

Appetites, tastes, and ability to eat may change as we get older or through ill health.

How do you as a carer recognise when something is wrong?

- Has your relative been losing interest in meals, surviving on tea and biscuits?
- Can they eat normally? Do they have ill-fitting dentures or a sore mouth?
- Do they have difficulty swallowing certain foods, such as meat? Issues to be

investigated by your Dentist or GP.

- Has your relative had a recent illness? Infection? surgical wound? They may need increased calorie intake at this time.
- Does your relative have difficulty using cutlery; is it painful to move around to get food or fluid?
- If you don't live in the same house, then check; is there food in the fridge or larder? Do their clothes look loose? Are there changes to their skin and hair? Are they tired or sleepy?

These physical changes as described can indicate a poor diet; they may also indicate a serious medical problem. Seek medical advice.

For more information on how to reduce the risks of malnutrition please contact your GP.

If you think someone is in immediate danger call the Police on 999.



Keeping Everybody Safe

Keeping Everybody Safe

Vulnerable to Abuse

Abuse can happen to anyone who is in a susceptible position. People who may be vulnerable include frail older people, those with a physical or learning disabilities or you as the Carer. Abuse can happen anywhere; at home, in care facilities or even in public. The abusers could be a family member, main carer or paid workers responsible for the vulnerable person.

What is abuse?

It is something that harms another person and affects their health and quality of life. The abuse can be constant or one event and may be premeditated or purely unintentional. There are lots of ways in which people can be abused.

Physical – Emotional – Sexual - Isolation – Neglect – Misuse of medication – Financial – Discriminatory.

So, let's ask a question – are you safe as a Carer, is the person you care for safe?

As a Carer you are often under huge physical and mental stress, you may be struggling to cope with demands or not have the knowledge you need to help you do the job. You may have your own health problems and feel tired and isolated. The person you care for may be confused, frustrated, and angry and seem ungrateful for your efforts. You may need a break from caring or extra help or knowledge to care

Abuse – if it is happening to you or your loved one get help.

Care Direct on 01202 454979
for Bournemouth or
Christchurch Helpdesk on
01202 633902 for Poole or
Dorset Direct on **01305 221016**
for Dorset Council.

enhance
learned about
information.
facts provide
details about

Carers Information Directory

Age UK free helpline

Providing direct help to over a million older people each year through their local services.

0800 169 65 65

Alzheimer's Society

Dementia Connect Service:

0300 222 1122

Memory Support and Advisory Service:

01305 259740

British Heart Foundation Helpline

Advice about all aspects of heart disease.

0300 330 3311

British Red Cross

Equipment Hire

0300 456 1914

Bladder & Bowel Continence Service Dorset (West)

01305 259978

continence.dept@nhs.net

Bladder & Bowel Continence Service Dorset (East)

01202 443111

dhc.continence.shelleyroad@nhs.net

Care Lines

Assistive technology; 24-hour emergency alarm monitoring service for elderly and vulnerable people. 24-hour 365 day. Emergency cover via pendant etc).

Magna Housing

01305 755800

Aster Housing

0333 4008222

Lifeline and Careline:

Bournemouth Careline

01202 452795

Poole Lifeline

Tel: 01202 733255

Carers Trust

0300 772 9600

info@carers.org

Carers Direct

Free advice and information to help you make decisions about your support needs and the needs for the person you are looking after.

01202 454979

Carers UK Carers line

Improving carers' lives through research, information and Campaigning

020 7378 4999

Carer Support Dorset

The lead carer organisation and main point of contact for carers in Dorset. At Carers Support Dorset they will register carers, complete a Carers Discount Card which enables carers to access discounts from local organisations, services. They can signpost carers to services, support groups and give information which they feel would help them to continue to be a Carer. As part of their service they are able to make requests for a Carers Assessment from Dorset Council. Carer Support Dorset

assists all unpaid carers in Dorset (excluding Bournemouth, Christchurch and Poole). If you are a Carer, please contact us or you can access information and make a referral via our website.

carersupportdorset.co.uk

0800 368 8349

admin@carersupportdorset.co.uk

Caring Matters

Free bi-annual Dorset-wide carers` magazine. To be added to the distribution list contact your local area.

Bournemouth, Christchurch and Poole area:

01202 128787

carersupport@bcpcouncil.gov.uk

Rest of Dorset:

0800 368 8349

admin@carersupportdorset.co.uk

Community Alcohol and Drugs Advisory Service

01305 214500

Continence Advisory Service

If you, or your loved one, would like to access this service and can attend a clinic in your area, please speak to your GP or any other healthcare professional involved with your care to arrange a referral. Alternatively, you can telephone the relevant office to self-refer or to ask for more information. The offices are open to enquiries from 8.30am until 4.30pm Monday to Friday.

Dorset Bladder & Bowel Continence Service (West)

01305 259978

continence.dept@nhs.net

Dorset Bladder & Bowel Continence Service (East)

Tel: 01202 443111

CRISP

The Carers Support Service is a small, friendly and helpful team, organising support and services through the Carers Resource,

Information and Support Programme (CRISP). CRISP provides support to help carers continue in their caring role while looking after their own health and wellbeing.

We are always at the end of the phone to offer advice, information and emotional support. We also have a free Carers Information Service to keep you up to date with social events, training courses, new services, and anything else we think might be helpful for you to know about through a bi-monthly newsletter.

crispweb.org

01202 128787

carersupport@bcpcouncil.gov.uk

Facebook: CRISP Carers

Twitter: @CRISPCARERS

Cruse

Bereavement care to promote the well-being of bereaved people. Call the national helpline.

08088 081676

Citizens Advice in Dorset

Confidential advice

including benefits.

citizenadvisedorset.org.uk

03442 451291

Citizens Advice Rural Dorset Service

Rural Outreach Advisors are able to visit people in their homes to give advice on a number of issues.

01308 456594 (Bridport)

Disability Living Foundation

Open Monday to Friday

Help and advice for older and disabled people.

0300 9990004

Dorset Cancer Care Foundation

Cancer care Dorset offers advice, information and support to anyone diagnosed with cancer.

General Enquiries:

Nikki Davies-Thomas

07593 890 879

admin@dccf.co.uk

info@dccf.co.uk

Dorset Carers Hub

01305751524

dorsetcarershub@gmail.com

Dorset Diabetic Eye Screening Programme

01305 898600

Dorset and Wiltshire Fire and Rescue Services

If you wish to book a Safe and Well visit, if you have need to reschedule or cancel your visit, or have any issues with your smoke alarms, please call this freephone number for the counties of Dorset and Wiltshire.

0800 038 2323

For all other enquiries

01722 691000

Always call 999 in an emergency.

If your call is not operationally urgent, or you need to make contact out of hours, please contact Fire Control

0306 799 0019.

enquiries@dwfire.org.uk

Dorset Counselling- Steps to Wellbeing Service Poole & Purbeck & East Dorset

A free, confidential NHS service for anyone aged 18+ who is registered at a GP surgery in Dorset (including Bournemouth and Poole) and in Southampton. They offer a range of different types of treatment for people experiencing problems with low mood, depression, anxiety or stress.

steps2wellbeing.co.uk

0300 123 1120 (*Listening project*)

Dorset NHS Clinical Commissioning Group

Providing community health services to Dorset including mental health.

dorsetccg.nhs.uk

01305 368900

Dorset Direct

Help and advice from Adult Social Care Services.

01305 221016

adultaccess@dorsetcc.gov.uk

Dorset Carers in Crisis

A back-up scheme which helps the person you care for in an emergency, when you are suddenly unable to provide your usual support.

Office hours: 01305 221016

Out of hours: 0300 123 9895

Epilepsy Action Helpline

epilepsy.org.uk

0808 800 5050

helpline@epilepsy.org.uk

GOV.UK

Public services in one place

www.gov.uk

Help and Care Handiworks PLUS

East & North Dorset and Purbeck

0300 111 3303

Headway Helpline

Help and advice for families following a head injury

0808 800 2244

Help and Care Carers Support

Telephone helpline, free information & support sessions, and other events in Dorset.

Short break service for Carers on behalf of Dorset County Council.

helpandcare.org.uk

0300 111 3303

Home Care Community Opticians

Home visit specialists. Covering Dorset, Wiltshire, South East Somerset and West Hampshire.

01935 813800

Huntington's Disease Association

0151 331 5444

Independent Living

Independent Living – the place for impartial information about products and services to help with mobility and independence.

independentliving.co.uk

Macmillan Cancer Support

Offering cancer information and support, open 7 days a week,

8am to 8pm

macmillan.org.uk

0808 808 00 00

Mencap

The voice of learning disabilities

0808 808 1111

help@mencap.co.uk

Lions Club Message in a bottle

Provide a bottle for people to keep their basic personal and medical details on a standard form in the fridge so that emergency services can easily access that information.

0345 833 4745

Motability Car Scheme
0300 456 4566

Motor Neurone Disease
mndassociation.org
03457 626262

Multiple Sclerosis Helpline
mssociety.org
0808 800 8000

National Dementia Helpline
0300 222 11 22

NorDIS
North Dorset Disability
Information Service also covers
West Dorset. Hiring equipment
and selling new and second-
hand disability aids.
01747 821010

NHS Direct
Non-urgent information and
advice on health issues.
nhsdirect.nhs.uk
111

**NHS Urgent and Emergency
Care**
Out of hours medical help.
111
Life threatening situations and
falls call **999**

Oakley Friends
Offer support, advice and
training for Carers for more
information contact Judy
Barnes.
01202 021705

**Older Peoples Mental Health
Teams**
Blandford: **01258 394045**
Bridport: **01308 426292**
Christchurch: **01202 858158**
Dorchester: **01305 250861**
Shaftesbury: **01747 475266**
Weymouth & Portland: **01305
762505**

**Patient Advice Liaison Service
(PALS)**
0800 587 4997

Parkinson's UK Helpline

Supporting people affected by Parkinson's.

0808 800 0303

PramaCare

Rated "outstanding" for care by the CQC, PramaCare is a registered charity providing Homecare services across Dorset and BCP

pramacare.org.uk

01202 207300

PramaLife

Offers advice and support and runs a variety of clubs, groups and activities, across the County of Dorset.

pramalife.org

Tess Champion, PramaLife
Bournemouth Manager

07912 272077

Carol Davies, PramaLife East
Dorset Manager

07736 133445

Bridget Barrett, PramaLife Poole
Manager

07867 354578/01202 207310

Radar Key Scheme

Purchase a RADAR key to access toilets with a RADAR lock.

Disability Rights UK

disabilityrightsuk.org

0203 687 0790

shop@disabilityrightsuk.org

Or from the following sources:

**Poole Civic Centre Main
Reception**

01202 633633

**Poole Museum Welcome
Centre**

01202 262600

Bournemouth Seafront Office

01202 451781

**Christchurch Information
Centre**

01202 499199

Rethink

National advice service helping those affected by severe mental health illness to recover.

0300 5000 927

Ridgewater Energy

Providing advice and assistance to homeowners, landlords and private tenants in assessing and sourcing funding and quotations for insulation, heating and renewable energy upgrades in the South of England.

ridgewaterenergy.co.uk

01202 862717

info@ridgewaterenergy.co.uk

Samaritans

Providing 24-hour confidential, non-judgmental support.

116 123

SSAFA

Help and support to those who serve or used to serve in our Armed Forces and their immediate family.

0800 731 4880

Stroke Association Helpline

Support to stroke survivors and their families.

0303 3033 100

Wheelchair Service

Helpdesk

01202 892874

Red Cross Wheelchair Hire

Open Mon/Tues/Thurs 10am to 1pm.

Cost of hire £15.00 per week.

01305 215951

Tax Help for Older People

Free advice for tax related problems for people aged 60+ on low or modest earnings.

taxvol.org.uk

01308 488066

The Leonardo Trust

The Leonardo Trust is the largest charity in Dorset supporting unpaid carers. They offer a variety of grants and support ranging from respite breaks and short holidays for carers and the people they care, Domestic appliances, educational courses and classes or home repairs and improvements as well as Carers Support Groups.

leonardotrust.org

01202 698325

info@leonardotrust.org

Transport - Linking Dorset

Business and organisations across Dorset are together launching an initiative designed to help people get out-and-about more across the county.

An array of transport opportunities, including local bus services community-based minibus schemes, community car schemes, dial-a-ride - and even use of statutory services vehicles for specific group activities - helps ensure those living in the area are not isolated.

Linking Dorset will provide a joined-up way of signposting people to transport schemes available.

Open 10am to 2pm on weekdays only

01202 586055



The Leonardo Trust
Helping People Who Care For Others



You're Looking After Someone But Who's Looking After You?

Are you caring for someone on a voluntary basis?
If so, you can apply for assistance from The Leonardo Trust.

Respite
Breaks

Educational
Courses

Much
Needed Home
Improvements

Financial
Support

Replacement
Appliances

Group
Funding

Leisure
Activities

Download an application form from our website, call us on 01202 698325 or email info@leonardotrust.org

www.leonardotrust.org

The Leonardo Trust is a registered charity No. 1086045



The Leonardo Trust

Helping People Who Care For Others

The Leonardo Trust was established in 2001 and is a registered charity providing financial assistance to unpaid carers.

We know that being a carer is hard work and finding time for yourself can be difficult, that's why we are the '*Carers Emergency Service*'.

Whether you need a short break, domestic help, sitting service, urgent repairs, furniture, domestic appliances, gym membership, driving lessons counselling, advocacy or something else we can help.

We can also support carers groups with seed funding, trips out, meals etc

For more information or to download an application form please go to our website:

www.leonardotrust.org

alternatively you can email

info@leonardotrust.org

or telephone **01202-698325**



In Partnership with



www.pramalife.org
contact the team on 01202 207329
Reg Charity No: 1172716

PramaLife FOCUS befriending and mentoring scheme

The PramaLife FOCUS befriending and mentoring scheme is available to you as a carer.

We can join you up with someone to regularly talk to (on the phone or face to face) or with a mentor who is an experienced carer themselves.

It will be an opportunity to talk things through with someone and have a bit of a breather from your caring duties. We understand that being a carer can be isolating and we can offer friendship and support to help you feel less alone.

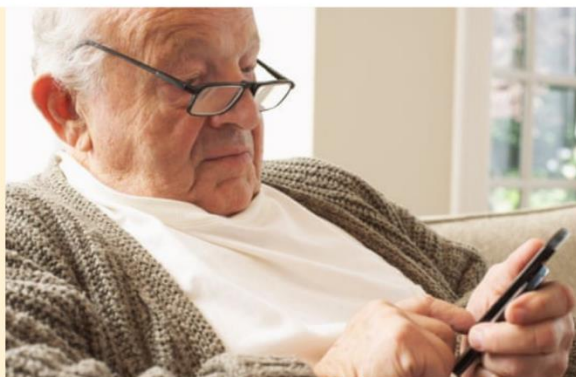
“ As someone who is new to a caring role, I had no idea how all encompassing it would be, I feel like I have lost a part of who I am, and I am now just ‘the carer’.

Through contact with befriender from PramaLife I have learned not to feel guilty for grabbing just 15 minutes ‘me time’ I am still overwhelmed - daily - with my caring responsibilities - but its nice to know someone is at the other end of the phone just for me

Debbie - Carer

A mentor can help you if you are new to caring or if your caring role changes. They can offer guidance, provide you with useful information and advice or their personal experience. All of our mentors have been carers themselves. A mentor can be available to you at any point while you are caring.

A befriender can meet you in person or chat on the phone, to offer friendship and a listening ear. They will keep in regular contact with you, as much or as little as you like.



To find out how we can help you, call the team on 01202 207329 to talk through your situation. All calls are treated confidentially, and if we aren't the right solution for you, We will try our best to signpost you to other support or help

www.pramalife.org

Can you offer some time to help?

We need volunteers to offer support for carers in the **Bournemouth, Poole** and **Christchurch** area.

We are constantly developing socially distanced services for people across Dorset, If you can help as a befriender, or want to run a telephone friendship group then get in touch. Volunteering is very easy to start, and it will make a huge difference in peoples lives.



As a befriender you will be matched with a carer who you can meet with or have a telephone friendship with. This will create a vital sounding board for carers or just allow you both to chat about something other than their caring duties.

This can be as little as 20 minutes a month

<https://www.pramalife.org/volunteering>

or call the Prama Team
on 01202 207329

As a mentor you will have cared for someone and be able to share your experience and offer guidance. We know this is invaluable to new carers and to those whose circumstances have changed. Some may be struggling to cope or feel overwhelmed and frustrated. You will encourage them to seek help or just to lend an empathetic ear.



Email befriending @pramalife.org.uk
or contact Diana or Mandy on 01202 207329
or send us your details via the website



 **PramaLIFE**
Age friendly communities

Friendship Line

Call us **01202 022987**
Everyday 10am - 7pm



You're never
alone
with
friends
on the phone

 **PramaCARE**
Supporting people at home

For more info call 01202 207300
or go to www.pramacare.org.uk

We are assisting BCP Council and the NHS by helping people who are leaving hospital. Our hospital to home service is here if you need some short term help, longer term care or end of life care.

- Domestic support
- Respite care
- Meal preparation
- Nail cutting
- Companionship
- Accompanied appointments
- Shopping
- Sitting Service



Inspected and rated

Outstanding ☆

For Care August 2019

Would you like to Host, or participate in Telephone Friendship Groups?



You can to speak to a group of people about a theme or a topic, or just have a conversation with a few others so that you don't feel like you're on your own?

Phone groups can take place any day at any time.
To find out more Contact

Keith on 07752 597334
keith.gubbins@pramalife.org



Please use this page for your own notes....

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