



## **Power of Attorney**

### **Dementia - Navigating challenging family dynamics**

In our contemporary world, families frequently find themselves separated by geography, time zones, cultural norms even language barriers, whether instigated by relationship relocation, overseas employment, emigration or natural or manmade crises.

Whereas international travel has traditionally held the appealing promise of glamour and adventure, these diverse family connections can cause heartache, delay or, worse still, disapproval or resistance to acknowledge reality when one family member begins to suffer the onset of dementia.

In these cases, the family member or friend on the ground, working hard to assist the person living with a life limiting condition, can find themselves facing differences in opinion in their attempts to secure Power of Attorney. Physical distance can add to the challenge of reaching agreement among geographically-spread family members with regard to a loved one potentially losing the capacity to make key decisions governing their welfare and finances. We humans are emotional creatures with strong family bonds, and it may simply be too hard for some to accept a dementia diagnosis for one of their own.

Philip has deep-rooted family connections to South America including with strong-willed and intensely private family members. Having witnessed in his youth a favourite aunt gradually develop dementia, Philip was acutely attuned to the early warning signs and recognised these as they started to manifest around the year 2000 in both his wife Helen, his sister and his wife's close sibling.

Philip picks up the story: "Helen and I have been married for many years and she was a smart, sophisticated, cultured lady from South America. So it was completely out of character when I discovered that she had purchased a timeshare in Florida.

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“Fortunately, I was able to have this strange purchase made null and void. Helen was diagnosed with a mild cognitive impairment which progressed rapidly, preventing her from driving and catalysing our desire to secure mutual Power of Attorney through our family lawyer. I was named as her Attorney and she as mine since this was what we wanted, and I’ve always been more than willing to fight her corner on both the welfare and financial fronts.

“I don’t in any way mean to make this sound like an easy process as it was quite the opposite - in fact her family in South America accused me of inventing the entire dementia diagnosis. That was immensely hard to take, and they refused to discuss any aspect of her care.

‘If I was to offer any advice to carers and family members looking after loved ones for whom they have Power of Attorney, it would be to remain completely open and honest in discussing what has been taking place. In all honesty, it sometimes feels as if you’re fighting an uphill battle to ensure they receive optimum care and support. In my wife’s case, I’ve arranged appropriate care through a blended team involving six personal assistants. I’ve also arranged loans to modify our home, including installing a new shower unit and a hoist in our bedroom.

“And you have to pay close attention to any and all medications that are being prescribed. In my wife’s case, the medication prescribed for her dementia-induced anxiety had been steadily increased over time and to a level more than double her recommended dose.

“We’ve also been through the mill with, in my view, a lack of dementia training for care workers based at our local day centre. Helen was always a compassionate, sociable and amiable person, however she was diagnosed with aphasia which negatively impacts her language and speech. As a result, when Helen was in distress she banged on the table which was deemed to be aggressive behaviour resulting in her exclusion. As a result of that exclusion, she now attends another area day centre though only as a drop in visitor.”

Philip’s experience with Power of Attorney for his sister has involved having to address distressing personal hygiene issues as she remains unwilling to regularly wash or shower, or allow care staff to clean and dress leg sores. In addition, her love of lighted candles posed a clear risk to health, thus Philip consulted with an occupational therapist before installing creative electric ‘fairy lights’ that have been well received while putting an end to the danger of open flames.

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It also transpired that benefits allocated for her care were not, in fact, reaching her bank account meaning that the care company was consequently delivering a reduced level of care. With more than a decade of experience acting for loved ones with dementia, Philip believes that his sister should no longer be living alone. In fact there have been so many misfires, mistakes and oversights in her care that Philip has been approached to allow his sister's experiences to become a learning tool for care professionals.

A third family member, Philip's sister-in-law Susan also suffers from dementia though she refuses entry to almost all visitors thus it has not proven possible to obtain a formal diagnosis despite more than 20 years of consistently deteriorating behaviour suggesting the condition. During that time, she has been the victim of several financial scams, including having been duped into purchasing more than £100,000 of effectively worthless artworks and wine, costs of which Philip has only been able to partially claw back.

When approached by overseas family members to also secure Power of Attorney for his sister-in-law, Philip was forced to decline since it would have been impossible to juggle care for both Helen and Susan. He did, however, locate a solicitor whom Susan could trust having taught him in her former role as an educator. Susan was involved throughout yet dragged her feet as she felt no real impetus to complete the process despite the risks so evident to Philip and his son. Philip's son is now Susan's nominated Attorney. Again, overseas family members accused Philip of an act of betrayal in securing Power of Attorney intended to protect his wife and sister-in-law.

Philip is aware of other carers similarly prevented from taking appropriate action – in their case to improve a parent's care - due to siblings, based elsewhere in the UK or abroad countermanding their wishes. And with these challenges based solely on telephone calls or short visits where the parent may have appeared lucid yet was in fact being irrational and showing clear signs of dementia.

With so many issues to contend with, like many unpaid carers Philip has called on support from carer organisations including [Mecopp Limited](#) and [Carers of East Lothian](#) (CoEL). The team at Mecopp has advised on pulling together a self-directed programme of care more tailored to Helen's needs while CoEL have also provided useful advice and welcome support.

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The last word must rest with Philip: "I've been advised by a specialist dementia doctor that you need to act quickly and decisively, and always remember that you're fighting a disease. Don't be afraid to complain though don't put people's backs up while doing so. And admit when you need help. You need to stay strong, focused and healthy to be able to help your loved one deal with this punishing condition."

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