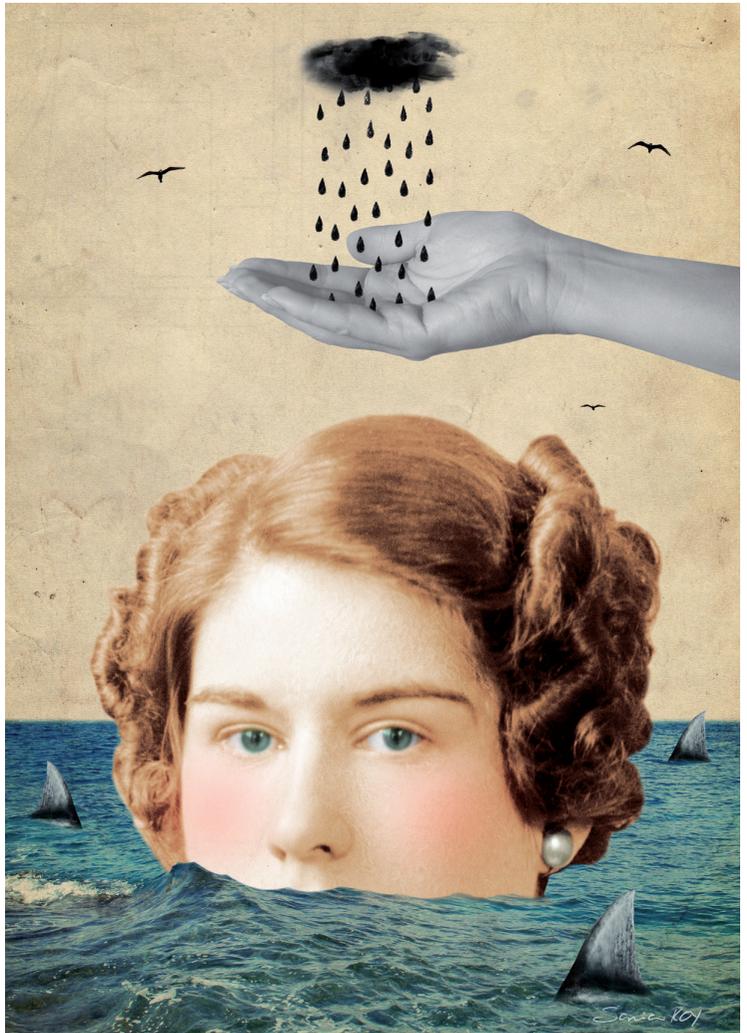


Guilt doesn't help.

EDITED BY MOYA SARNER ILLUSTRATIONS SONIA ROY

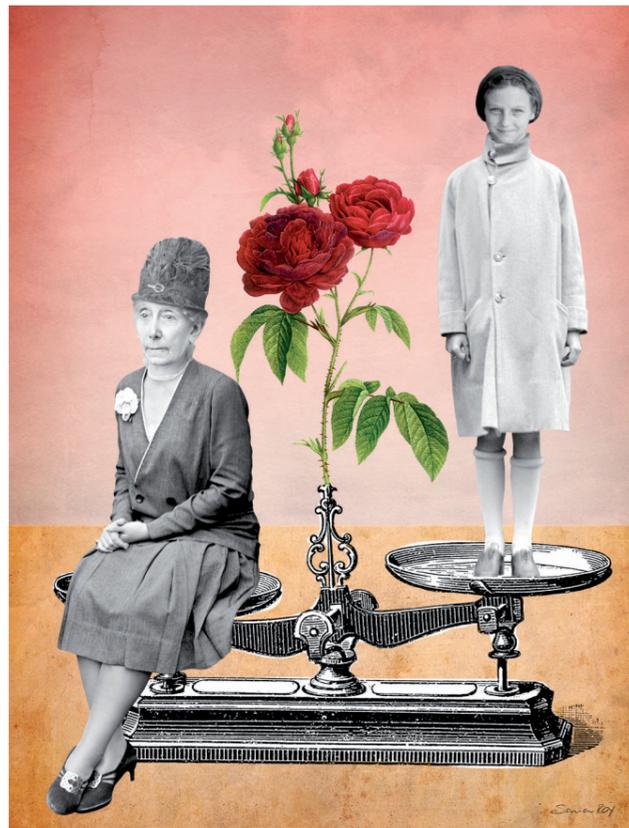
THIS WILL!

It's coming. The time when the people who looked after you need looking after themselves. As these five writers show, it's a situation that demands so much of you, but if you support your parents with compassion, the experience can be cathartic and rewarding. Whether the storm is approaching or it has already hit, we'll help you find the courage and know-how to weather it...



SONIA ROY AT COLAGENE.COM





DECIDING WHO NEEDS ME MOST

Guilt is the emotion that can tear you apart as you try to do the right thing. So you have to find your way through it. **BY LOUISE VOSS**

One of the lowest points for me was after I'd written to Mum's friends and neighbours to tell them she could no longer live safely at home (as many of them well knew, having been recipients of 3am visits from her, or after witnessing her wandering into roads). I gave them all her care home address

and asked if they could visit her regularly to keep her spirits up. Then I received a reply that shocked me: 'It's not fair to place the burden of care for your mother on the shoulders of her friends, when many of us are old and infirm ourselves. She should be with her family.'

Every time I even thought of the letter for weeks afterwards, tears welled. I was only asking them to visit her, not have her

move in with them! I mentally composed all kinds of impassioned defences – but thankfully didn't send anything. More distressing than the rudeness, though, was the guilt. This friend was right – in an ideal world, Mum should be moving in with my brother or me. But we had jobs, and kids to look after, and I'm divorced.

That's when I realised: when you're a carer, all roads lead to guilt. I could move my mother from Salisbury to London, so I could visit more often – but that would have meant moving her from where she had lived for 50 years. I could have moved from London to Salisbury – but my daughter Gracie was about to start her GCSE courses and was devastated at the thought of changing schools. I was being pulled in two directions, and I felt whatever I did would make me either a bad mother or a bad daughter. I developed hideous insomnia and went on anti-depressants, all the while watching Mum's condition worsen week by week.

Finally, we found a solution – Gracie moved in with a school friend on weekdays. Again, I felt guilty about imposing on this girl's kind and generous mother; but I gratefully accepted her offer, and I moved into a rented cottage near Mum. It wasn't easy – Gracie struggled being away from me during the week, and when she rang me in tears saying she missed me, I felt absolutely terrible.

But in hindsight I know it

was the right decision. I was able to spend time with Mum while she was still well enough to enjoy trips and lunches out and knew who I was, most of the time. A year on, she's now too ill to do anything and doesn't recognise anybody, and I realise my time with her was precious. I can see, too, how the experience taught Gracie independence and resilience, and she appreciates me more. So I don't regret my choices.

But I do regret the guilt I felt. My experiences have made me realise how futile it is to feel guilty. Every time I feel it creeping back, I think of Mum saying – as she would – 'Of course I don't want you to give up everything to care for me. I've had my time, go and have yours!' I have to make a conscious effort not to torture myself by imagining that I've abandoned Mum or let her down. These overly emotive words are harmful. I've found that gratitude is what helps most, so when I start getting sucked under by guilt I try instead to focus on the positives in my life: my daughter, career, health, friends – and how lucky I am to have had such a wonderful mum for more than 40 years.

It's also made me realise that if I need care, I will not allow Gracie to go through all this self-doubt, confusion and pain. We will have those conversations while I am still able. I want to make sure the guilt stops here.

FOR MORE OF LOUISE'S WRITING, TRY HER NOVEL, THE VENUSTRAP. ILLUSTRATIONS: SONIA ROY AT COLAGENE.COM

CARING FOR THE PARENTS I ONCE TURNED MY BACK ON

If you meet those you care for with an open mind, and an open heart, regardless of what went before, you may find a long-lost love hidden in the distance. **BY CAROL LEE**

Families hide many things. Mine hid its love.

I didn't know this until a phone call one July day in 2006, when I was told that my father was in hospital more than 200 miles away. My response was automatic: I drove from London, where I lived, to my parents' home in South Wales. Yet my relationship with them hadn't been close for decades.

The rift began a few weeks after my 10th birthday. My father was an engineer and we were

living in East Africa, in a bush settlement with no school. I was sent 5,000 miles away to relatives in Wales, to a school where I was bullied. Overwhelmed by hurt and a sense of abandonment, I began to sink. I didn't see my parents again for more than two years, and I survived by deciding to get on with my life alone. I turned my back on any thoughts of them and we grew apart, this rift between us never spoken of.

But driving to Wales that day nine years ago, none of this was in my mind: in its stead, just an urgent need to protect my father.

He had pneumonia, which would have killed most men of 85, and the sight of him, alone and bewildered, seared me. 'Come on, Dad,' I said, taking his arm, 'we're going to get you out of here'. And we did.

There followed two and a half years of driving up the M4 to take care of two households, the surface miles only a fraction of the unseen journeys. My parents and I were travelling towards each other at last. Through tales of my parents' childhoods, I began to feel for them: my father left in an orphanage because his mother was ill; my mother kept back from school, which she enjoyed, to look after five younger siblings. The hidden love began to emerge as I listened and understood.

Gradually, I came to love them both. Mum and I baked, went blackberrying, and laughed as a stiff breeze shrouded me in a sheet as we hung out washing. We three did crosswords and played Ludo, cards and I Spy, a game that had encompassed all of our childhoods.

It was still an exhausting business. The 5am start for a blocked drain in Wales, the shopping, cleaning, cooking,

washing, hospital appointments, doctor's appointments, eye tests, X-rays and the beginnings of my mother's short-term memory loss. I had my full life in London, too. Suddenly I was stretched to my limits. The strain told in my weight loss, sleeplessness and the deep guilt that I was never doing enough. The most important task of all was the one I couldn't see at first: just being with them. 'I feel so safe and warm with you in the house,' Mum said to me one night, filling me with regret, for I knew I would be leaving again the next morning. I was a mass of emotions – joy among them.

By the time Dad died, aged 87, two years after that phone call, I was glad for him. But when Mum, who hadn't been ill, died eight weeks later, it stopped my heart. I'll always be their daughter. I feel this as I travel to Wales, to the little house they left, now my second home. I've been lucky to be left with many gifts: as well as the house, my book, *Out Of Winter*, about my time spent caring for them; and, most of all, a sense that I'm a better person. Bigger, more compassionate. More loving.



MY LESSONS

1. Activities are very important. My fondest memories are of us doing things together. Research has shown how vital it is to simply go through old photos or sing favourite songs.
2. Don't underestimate how much your physical presence matters: just being in the same room is a comfort.
3. Bring in as much help as possible, from neighbours, friends or official channels, so the burden of care is not entirely on you.

FACING UP TO THE FEELINGS NO ONE TOLD ME ABOUT

The person you're caring for may be difficult, moody and irascible – but it's your own emotions that will shock you the most. You will need to learn to forgive yourself. **BY MARIANNE TALBOT**

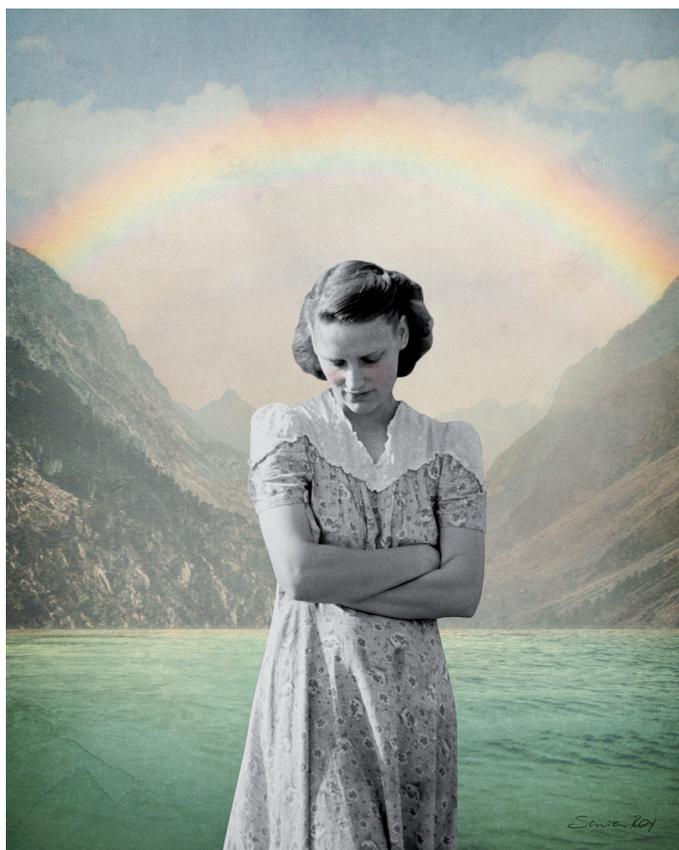


ILLUSTRATION: SONIA ROY AT COLAGENE.COM

The Valium was working, my sobs were subsiding, but it was clear that I couldn't care for Mum any longer.

Mum had moved in with me when she was diagnosed with Alzheimer's. It had taken me a year to decide to invite her, and, having always lived alone, it was a shock to share my space with someone else, even my beloved mum. We

bickered, of course, but we had always enjoyed each other's company.

At first she was her usual confident, intelligent and cheerful self. We went to the cinema and the opera. We dined out and gave tea parties. We'd sing raucously while washing up. Then we'd watch television companionably until bedtime.

But then she became incontinent. She could no

longer read, sew or do anything for herself, and she was vulnerable, isolated and clingy. Every night she'd ask heart-rendingly: 'Is it time to go home? Please let me go home.'

What was harder to deal with was her anxiety, and occasionally she could become angry and lash out. Once, when I was helping Mum with her socks, she kicked me in the face. It was obviously malevolent. Slamming out of the room, I waited outside until I stopped trembling. I was so close to losing control myself.

I was often angry and frustrated while caring for Mum. I was angry because I was stressed, anxious, fearful and sleep deprived, because my lovingly prepared meals were uncompromisingly rejected, and because I often failed to get Mum to the loo in time. Sometimes I felt furious

because, like so many carers, at times I felt trapped by the responsibility, and not in control of my own life.

Fury is one of the most disabling emotions. It corrodes your very being. If you are a carer, expressing anger is all but impossible. You have to be thankful with helpers, and controlled with the person you are caring for.

The only way to manage it is to tell yourself it's okay to be angry, that you will let it out

later – and then find a way to do that. For me, it was writing my blog, which became a book, *Keeping Mum: Caring For Someone With Dementia*. The hundreds of emails I received in response told me that all carers feel this anger – we are not saints, we are real people doing an impossible job. But in our heart of hearts, we know it is one of the most important jobs in the world.

Mum went into a home for the last six months of her life. I couldn't cope any more. I was distraught. I had committed myself to caring for her until she died, but I simply couldn't. The guilt was terrible. I know now that this is common. When I talk to other carers, I make a point of stressing that a home will almost certainly be necessary at some point. Sometimes only professionals will do. I wish I had realised this. Instead, I felt I had betrayed Mum.

In fact, Mum loved the home. Six months after she went in, she died. I was with her, and in her last hours she repeatedly called me Mum. I hope this meant she felt secure. That's when I knew having her live with me was the best decision I've ever made.

I miss Mum. But I don't miss the anger that I so often felt as a carer. That passes, thank goodness. But the love – that endures.

- MY LESSONS**
1. It is okay to be angry – you have plenty to be angry about.
 2. Find your own way to let off steam, whether it's phoning a friend, writing or taking up boxing.
 3. Discuss your anger with other carers – they will understand.

ENDING UP BACK IN MY CHILDHOOD HOME

At some point, all carers wish that they could go back in time, to that place in our memories when our loved ones were well. But it's true what they say – you can't go home again. **BY JILL SINCLAIR**

When I moved back to care for my dad, he was still living in what had been our family home for almost 50 years. The walls were still covered with photographs, there were still books in every

room, there was still that orange and brown carpet where I'd spent my teenage years sitting cross-legged, listening to Led Zeppelin. Only now, Dad slept in 'my' room; it was easier for manoeuvring the hoist to get him in and out of bed. His piano, which had been such a focal point, was now a

dusty relic, and the dining room table, host to so many boisterous family meals, was a dumping ground for unanswered post. Instead of tripping over the cat, I was tripping over Dad's wheelchair, and answering the door not to my friends but to deliveries of medicines and continence pads.

I decided to move back to Glasgow when Dad's dementia became too difficult to manage from 400 miles away. After two bouts of pneumonia, I believed he only had months to live. But it turns out most people die with dementia, not from it, and that was true of my dad, who lived for two more years.

So the phrase 'moved back home' isn't really truthful. The house was much the same, but 30 years after I'd last lived there, it wasn't quite the home I remembered. Dad had always been so particular about language but now he could hardly string a sentence together, often talking complete nonsense, thinking he was making perfect sense. Where before he would take care of all the running repairs, now he could barely even feed himself. I don't have children and wasn't entirely sure how I'd take to 'helping with toileting' – a euphemism for wiping Dad's bottom. But I soon realised that the world is divided into those who are squeamish and can only back away, and those who just roll up their sleeves and get busy. It became very matter-of-fact and we just got on with it. Our roles had reversed – now I was

the carer, he the child.

But there were changes that brought me light relief, too. The neighbours appeared like angels, bearing strawberry tarts and insisting I go out with them for coffee, where they told me stories about Mum and Dad when they were much younger – probably around the age I am now. It helped me to be reminded that Dad was a proper human being, and not just a demented old man.

I stopped looking for help from the obvious places – the friends and family members who didn't support me, medics who only saw Dad's illness. The Alzheimer's Scotland staff became my surrogate family, and I made new friends as part of Glasgow's Glad Café choir, singing to Dad after rehearsals. He always smiled and sometimes laughed – with pleasure, I think, rather than in horror!

Would I have decided to look after Dad if I'd known it was going to be two years, rather than a few months? It was sometimes lonely and often unspeakably sad, but it never got too much. I knew I was giving him the best possible care, and I am grateful for the time we had together. Now I'm back in London and in the process of getting my life and career back on track, and the old house with the orange and brown carpet has been sold to a lovely young family. I still think about the people I met regularly at the local park while caring for Dad, who were there feeding the ducks on the day of his funeral. They pointed to the new ducklings as if to say, 'Life goes on.'

MY LESSONS

1. Keep asking for help – and don't rule out support, however unlikely or unexpected its source.
2. Don't expect a consensus on what's 'best'. Caring and carers can be a very fertile battleground for families.
3. Keep one eye on what's ahead. While Dad was sleeping, I wrote my first book, *The Art Of Being Ill*, which gave me something to focus on once it was all over.

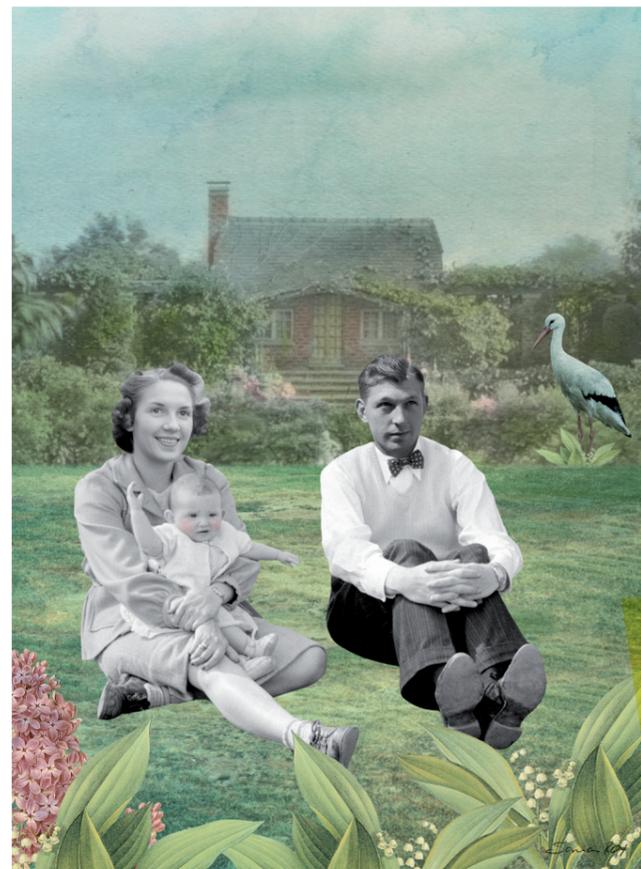


ILLUSTRATION: SONIA ROY AT COLAGENE.COM

FINDING SIMPLER WAYS TO DEMONSTRATE LOVE

As regular channels of communication close down, opening up new routes to understanding can help you see the light in the darkness. **BY SUSAN WILKINS**

I suspected all was not well with my mum when she started writing on the kitchen walls. Phone numbers, addresses, instructions on how to operate the microwave – she loved painting and drawing, splashing colour around, but this seemed outlandish even for her. 'I forget things,' she said indignantly when tackled. 'I'm 84. What do you expect?'

Several months later, after a battery of tests, she was diagnosed with vascular dementia. My father went into a sulk. He refused to discuss her condition with me or her doctors, maintaining that she was just being awkward to annoy everyone. He sat stubbornly behind his newspaper, a frail old man with his own health issues, refusing to acknowledge that his world was falling apart. She wandered round in states of undress. I went in every day – fortunately I only lived five minutes away – and additional carers were hired, rotas set up.

How do you find a way to communicate with your parents when one of them can't, and the other won't? We muddled on for a couple of years. There was no family discussion, no acknowledgement of the crisis. I had no siblings to support me, and my father remained in denial. My parents belonged to the generation who'd fought the Second World War. Their mantra was: life is tough, just get on with it. They expressed love with a hug, an affectionate pat on the arm, a fiver slipped in your pocket. The notion of endlessly discussing feelings



Sonia Roy

they regarded as self-indulgent.

My mother seemed to be going deaf, but the doctor explained that it wasn't her hearing; she was losing the capacity to identify the meaning of words. I bought her a notebook, pencils and crayons, and urged her to write and draw. She wrote addresses – my address, her address – desperate to get them right, copying them several times. She drew small stick people; her pictures became more child-like, and then just scrawl.

When I visited her in residential care, we'd sit down together and go through the

MY LESSONS

1. You will have to find new ways to connect with your loved ones – whether it's music, art or touch.
2. Remember your need to talk about what's happening may be greater than theirs: communicate on their terms.
3. There will be moments of light in the darkness, but you have to be open to see them.

book. I'd admire what she'd done and that would please her.

The last time I saw her, she squeezed my hand. I looked into her eyes – blue like mine – and I realised that, although most of her words had gone, she was still there. She was regarding me with a kindly eye and, for an instant, all the battles of life fell away, all the traumas of me growing up and her growing old. We both understood that she was leaving but that her love would remain. That's how you learn to communicate, when all channels are closing down. With love.

HOW TO GET THROUGH

Every carer has a survival kit – for starters you will need:

A GOOD LISTENER: Whether it's a friend, a counsellor, or even the dog, you will need someone to rant to.

AN OLD SONG: When it seems all memories are lost, music and lyrics often remain. Having a good old-fashioned sing-along with your loved one may help you both to reconnect.

WINE: No explanation needed.

A BOX SET (OR SEVERAL): Sometimes you just need to escape into a brilliant TV series

you can watch late into the night. Some of our favourites: Orange Is The New Black, Homeland, The Bridge.

OLD PHOTOGRAPHS:

Because they weren't always like this. They were once that handsome young couple on their wedding day, they were once the proud parents holding you in their arms. They have lived lives filled with love and laughter, and remembering that may help you to sail your ship.



FREE HELP

★ In England, the NHS will cover nursing costs through **Continuing Healthcare**.

However, be aware that it's difficult to qualify.

Different rules apply elsewhere: contact your local NHS trust or board to check entitlements.

Anyone over 65 qualifies for an

Attendance Allowance towards care costs. The lower rate is

£54.45 a week, the higher, £81.30 a week: claim at gov.uk or call

the Attendance Allowance Helpline on 0345 605 6055. For

N. Ireland, call 0800 220 674 to check disability living allowance.

★ Find a **care home** via the

Care Quality Commission website, cqg.org.uk, and findme

goodcare.co.uk. Outside England or Wales, go to scottishcare.org

or rqia.org.uk. Look for homes with extra support for dementia

sufferers via the Alzheimer's Society on 0300 222 1122.

★ **Voluntary help:** Age UK or royalvoluntaryservice.org.uk

★ **Also visit** myagingparent.com and ageuk.org.uk.

3 THINGS YOU NEED TO DO RIGHT NOW:

1 SET UP A LASTING POWER OF ATTORNEY (LPA)

While your parent still has mental capacity, ask them to set up an LPA to give you authority to make decisions on their behalf. It takes up to 10 weeks and costs £110 to register – or more if you're taking legal advice. In England and Wales* there are two types of LPA, one for welfare and one for finance and property, and the latter can be activated while your loved one still has mental capacity. Note: you cannot apply for either – they need to.

2 ORGANISE A LIVING WILL

A living will sets out wishes regarding medical treatment – for example, the wish to stop life-prolonging treatment when unconscious. It can be drawn up by solicitors at the same time as a standard will at a relatively small starting cost of £75, going up to £300 depending on the solicitor. Go to solicitorsfortheelderly.com to find a lawyer. A living will is only binding if the person making it has mental capacity at the time it is drawn up, and they clearly state the circumstances and specific treatments they would either agree to or refuse.

3 CONTACT SOCIAL SERVICES

Contact your loved one's local social services department, and ask for a needs assessment to find out what help they're entitled to – you can ask for your needs as a carer to be assessed, too. Talk to their GP as well. □

CAN YOU TRUST THE CARER?

Local authorities can provide home carers or personal assistants, but if your parent is eligible for care-at-home funding, you can ask for this money to be paid straight into their account and employ someone yourself.

The easiest option is to use a care home agency that can deal with police and employment checks, payments and tax – but be prepared to find yourself paying £5 to £10 extra per hour for this benefit. Go to the UK Home Care Association's website (ukhca.co.uk)

to find an agency.

If you employ a home carer yourself, you'll have to handle all the paperwork as if you're an employer – but you will be in total control of who you hire.

TAKE NOTE: You can't pay friends or family to do this unless they are a registered carer.

You'll need to check that any potential worker is eligible to work in the UK: ask to see a passport or other ID to prove they're from the EU or have a work visa. It's also vital to get a Criminal Records Bureau check on any prospective employees

before you interview them or let them into your home. Don't forget to take out Employer's Liability Insurance and Public Liability Insurance, and write an employment contract that includes details of specific tasks, working hours, pay, duration of contract and holiday entitlement.

AFTER YOU'VE HIRED:

If something goes wrong, speak directly to the care home or agency about your concerns and how they can be resolved. It's worth writing down your issues and keeping a

paper trail as evidence if a complaint hasn't been dealt with.

If the local authority is funding a carer who you believe is being dishonest or neglectful, contact the local Adult Safeguarding or Protection team – you can get details from social services.

If you're unhappy with the way your complaint is being dealt with, contact your local government ombudsman via lgo.org.uk – and the Disability Rights UK Independent Living Advice Line (0300 555 1525) can also offer support.

WORDS: NATHALIE BONNEY; ILLUSTRATION: SONIA ROY AT COLAGENE.COM; *POWERS OF ATTORNEY DIFFER IN SCOTLAND AND NORTHERN IRELAND. IN SCOTLAND, A CONTINUING POWER OF ATTORNEY COSTS £70; IN NORTHERN IRELAND, AN ENDURING POWER OF ATTORNEY COSTS £115