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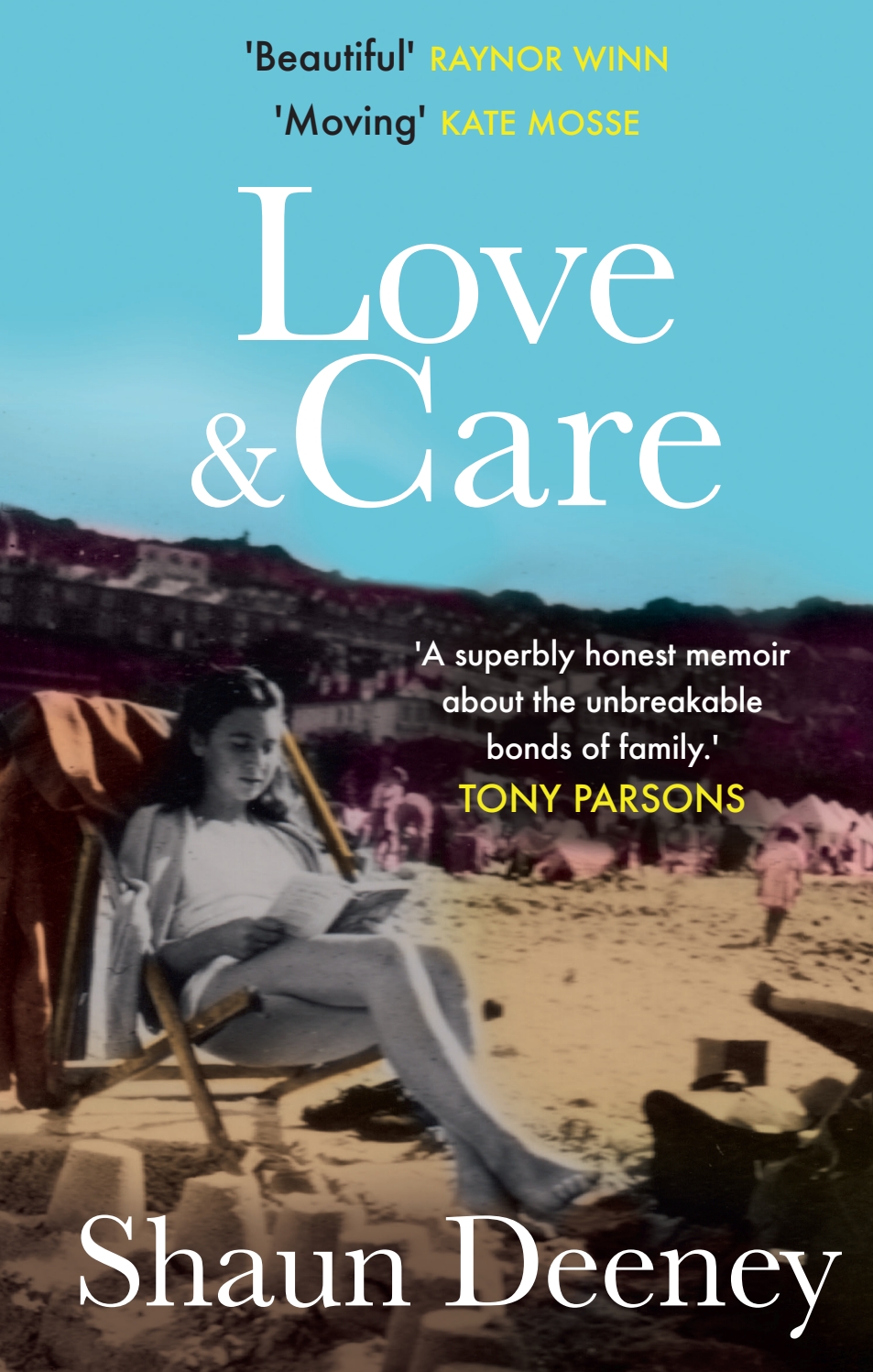
Love & Care



'A superbly honest memoir about the unbreakable bonds of family.'

TONY PARSONS

Shaun Deeney

LOVE&CARE

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ENDEAVOUR

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Some names and identifying details of characters in this book have been changed.

For Megan and Leah,
Karen and Pam

'For it's so clear that in order to begin to live in the present we must first redeem the past, and that can only be done by suffering, by strenuous, uninterrupted labour.'

Anton Chekhov, *The Cherry Orchard*, Act II
Translated by Julius West

'If you tell people the truth, make them laugh or they'll kill you.'

George Bernard Shaw

BEFORE

I hold my mother under each arm as she takes tiny shuffling steps towards the car, and open the passenger door to ease her slowly back onto the seat. I lift her skinny legs one by one into the footwell and make sure her slippered feet are flat on the floor.

'Where are we going?' she asks, as I lean over to buckle her seat belt.

'For a rest,' I say, 'to a nice place. With your own room.'

'Why?'

I can't tell her why. So I lie and say this will only be for a week or two, just to give her a break. 'Like a hotel.'

The care home is a 1930s red-brick building with turrets, no doubt built as a grand home for a wealthy family. A carer meets us in reception and leads us through to the day room.

The residents sit in high-backed chairs, homogenized and diminished by age. Many are huddled beneath blankets with their heads bowed in sleep, but as we pass a woman in a tweed skirt with neatly bobbed hair and the earnest face of a teacher, she reaches out, her voice pleading. 'Nurse! Nurse! What should I be doing?' A man on a gurney, his arms writhing, is shouting, his voice shrill and echoing through a space that is otherwise oddly silent.

The carer leads us to a vacant chair tucked away beyond a baby grand piano under a green cover. Together, the two of us try to settle Mum in, though she stiffens and resists as we ease her backwards to sit. The carer brings a dining-room chair for me and offers us tea. When she goes, I try to think of something reassuring to say to Mum, but the thought of my own complicity in bringing her to this place chokes my words. How have I allowed things to come to this? Why didn't I do more?

Three weeks earlier, I had been called to an emergency meeting with adult protection services, social workers and the police. They examined the written reports from social services detailing my father's treatment of my mother – he was not physically violent, but there was evidence of neglect and rough handling – and I told them about my own experience of his cruelties and controlling behaviour over many years, beginning long

before her diagnosis of Parkinson's dementia. The ten or more officials around the horseshoe-shaped conference table, some in uniform, were sober and serious as they listened to me and read from the papers in front of them. There was more discussion that did not include me, and then the head of adult protection said the only possible course of action was to remove my mother from potential harm. He made it clear that because she lacked the 'mental capacity' to bring a formal complaint against her husband of fifty years, neither social services nor the police could act unless I could persuade my father to give his permission for her to go into a care home.

And so, with no other choice, we circled him. By citing his heroic efforts to take care of his wife, the sacrifices he was making for her and the impact on his own health, I flattered and then cajoled him into agreeing to a short respite stay for my mother. The official intention was to address the situation and to ensure adequate safeguards were put in place to protect her in her own home. But I knew, and I think the authorities did too, that my father would never change, and that Mum's move to the care home would very likely be permanent.

The carer smiles reassuringly as she returns, wheeling the tea and a piece of cake towards us on a laminated hospital table. She tells me her name is Cai. She offers to sit with my mother while I take her bags up to her room.

'Go, go,' she says. 'Mum is okay with me.'

The room is cold. It has a hospital bed, a wardrobe, a dresser, and a small window overlooking the garden. The en-suite bathroom has handrails and a shower chair and is even colder than the bedroom, and though there's nothing to object to – the place is clean and uncluttered, with plain magnolia walls – there is little to love. I unpack my mother's dresses and cardigans, checking I've labelled everything with her initials in black permanent marker before hanging them in the pine wardrobe. I put a few photos of the family on the dresser and two pairs of shoes under the bed.

When I go downstairs again, Mum is alone in her chair, her tea half drunk and an empty plate with cake crumbs in front of her. I sit beside her and tell her I've put her things away. I say the room is lovely, but as I lift the wing-handled plastic cup to her mouth, I see her bottom lip is quivering and her eyes are darting this way and that, hunting for threats. I notice she is trying to speak, but her voice is weak and soft and I can't make out the words.

'What is it, Mum?'

'I want to go … to go …' she says, stumbling over her words, '… home now.'

The profound simplicity of her plea stuns me. I can think of nothing to say. At least nothing that is true. So I tell her we *will* go home, in a few days, and that

meanwhile she should think of this as a holiday. I spend another hour talking about anything I can think of to distract her – my two daughters, work, the weather outside – but nothing consoles her, not even when I say I'll be back in the morning to spend the day with her. I feel certain she sees through it all. She knows this is not a holiday. Even with the fog of dementia, she understands it is all wrong. She knows she has been taken from her home and her husband and all that is familiar. What she doesn't understand is why.

The time comes for me to leave. I ask another of the carers to sit with her. I kiss my mother on the forehead, and her face creases with emotion. She is stumbling over her words, but I hear 'Don't … don't … don't …' repeated over and over as I walk away.

By the time I reach the lobby, I see the carer on her haunches in front of Mum, patting her hand, and my mother with tears rolling down her cheeks. I feel my heart breaking.

WINTER

It was late November, eighteen months after I had taken my mother to the care home, when I got a call to tell me my father was dying.

I was sitting in the shade of the medieval arches of a bar in the middle of the Sommières Saturday market. The midday sun of the south of France was as hot as an English summer scorcher. The sky was entirely cloudless and the brightest of blues. The carafe of cheap rosé I'd ordered, as I always did on my weekends off, was down to the last glass.

'He's in hospital again … and he's not eating at all …'

It was Brenda, who ran the care agency that had been looking after my father since my mother had gone into the home. She called me from time to time so I could keep tabs on him without our having to speak in person. I was used to tales of his bad behaviour, poor eating habits and refusal to leave his bed.

I had been living in France for the best part of a year, sharing a broken-down farmhouse with my oldest friend Phil, an architect, working on a house he had designed and using my spare hours to write a book. I had been back to England four times to visit my mother in the care home, but I had cut off all contact with my father. For years I'd tried to buffer his worst excesses. Now, with my mother safely out of his reach, I was free of all that. Friends and family had long ago given up on him, and he was alone in his house, save for three visits a day from carers, who would try to get him to eat and see to his personal hygiene. Angry with me for having deserted him, as he saw it, he told anyone who would listen that I was a menace and very likely bipolar. I don't think it ever occurred to him that it might be his own mental health that was the problem.

'Perhaps you should think about coming back,' Brenda said. 'I have to tell you, I don't think your dad will be going home this time.'

We said our goodbyes and I poured the remains of the rosé into the glass. The tables around me were heaving with chattering customers, their tables littered with the shells of oysters bought from the market. Waiters squeezed through the crowds with trays of carafes and glasses. After a long week's work on the building site with only Phil for company, I came to this bar for the people and the bustle of life, but all at once I felt isolated and alone.

I had seen the deterioration in my mother on my visits to her in the care home. The progressive effects of Parkinson's dementia had made her frail, and she was now unable to stand or walk or feed herself. But it was also her spirit that was sick. She had been taken from her home – I carried my own burden of guilt for that – and I knew she felt that loss every day, because when I sat with her in the day room, she would beg me not to forget her and not to leave her there. I had accepted from the very first day that Mum would likely end her days in the care home. Still, I had made promises to her that I would one day bring her home. I hated myself for doing so, and I never thought for a moment that those promises might come true.

All I could understand about my father's impending fate was that everything would change because of it. I didn't want to go, but I knew I would book a ticket as soon as I got back to Phil's farmhouse. Though what this trip would hold – for me, for my father, and though I hardly dared voice the thought, for my mother – was too much to take in.

And yet this was supposed to be my time. I had done what I could for others. I had survived divorce and given up my career as a television producer to work in a local off-licence so I could be there for my two young daughters, who were six and twelve at the time. I had been through the break-up of a long and loving relationship

with my post-divorce partner, Marie, and still I'd carried on writing, surviving on my dwindling cash in the bank and a variety of part-time jobs – as a psychology teacher and a paella chef, as ground crew helping to launch and recover hot air balloons on pleasure trips – until finally I ran out of money and into a brick wall very like full-blown depression.

I had come to France to make a fresh start. By working with Phil and living in his farmhouse, I had just enough money to survive. My girls, now grown up, had been to visit several times, and I could finally finish my book. I was free and single, and although I was in my mid fifties, I was still hoping I might find love once more. Now, history was repeating itself, and once again I was being dragged back by all I had left behind.

I take a cab from the airport to my parents' deserted bungalow in the Surrey suburbs, arriving just as dusk is turning to night. A frost is already forming on the pavements and the lawn. I have a key because I have been here so many times before, but never to an empty house.

Inside, it is dark and cold. I see the door to my father's bedroom is open but the heavy lined curtains are closed. The blankets on his double bed are thrown back and dishevelled, as if he's only just been wheeled to the waiting ambulance. There are used tissues on the

floor. His portable Roberts radio is on the cabinet by the bed, aerial extended. There is the scent of old man.

This is his home, with his things. The reproduction paintings in the front room reflect his taste for bucolic Constable prints, scenes of Cavaliers carousing, and picturesque Dutch windmills in soft evening light. The dark-wood sofa and armchairs padded with squeaky faux leather are his idea of luxury. The glass cabinets in the dining room are brimming with Waterford crystal and dotted with model aeroplanes on cheap plastic stands, along with his golf trophies.

My mother lived here too, and not long ago, but there is no sign of her, nothing she once loved or cherished, or that truly speaks of her. Her role as wife and mother was always to support my father. She was confined to the background, an attendant to my father's needs and desires, long before the ravages of Parkinson's dementia undermined her ability to express herself in words or actions. She was quiet and competent, sweeping behind us all, ready with plasters to salve a graze, a consoling hug for school reports, a favourite dish – lemon meringue pie with home-made pastry so buttery it makes my mouth water even now. But she never talked of her own needs, and when I was a boy, I took her for granted entirely. If I had rowed with Dad, she would come to me in my room when things had died down, bringing a treat to keep secret, finger to

her lips to shush me, and always with that smile of hers, a smile of forbearance and infinite understanding, the smile I have so seldom seen in recent years.

As a grown man, still ignorant of her real needs, I would ask her what she might like as a present for Christmas or birthdays. She would say, 'There's nothing I need. Don't spend your money on me.' When I probed, she would struggle to come up with something for the kitchen or the garden, saying, 'Your father thinks we should have …' I would hug her and tell her she was a saint and buy her ridiculous bath oils, or a silk scarf, or a Georgette Heyer novel in hardback.

Mum has been gone from here for a year and a half, and yet her single bedroom is still littered with the paraphernalia of incontinence pads and wipes. Her clothes, the photographs that were once here on the chest of drawers, and the hairbrush she loved, all these things I took to the care home, but otherwise the room is as I remember it. Two or three times I came to stay for weekends to help care for her, but my father did not like my being here and told me not to come again. I recall holding her under both arms as we returned from the bathroom and easing her back to sit on the bed. Changing her into her nightdress and then helping her to lie down, lifting her legs as my father stood by exhorting me to 'Use the handrail, that's what it's there

for.' He had had a workman screw it to the wall, but my mother could never reach it by herself. That always made him angry with her.

I clear away the mountains of medications, find some sheets and pillows and a duvet and make myself a bed for the night. I turn the central heating up high, acutely conscious of being the only living being in the house. In the kitchen, the fridge is all but empty, and I didn't stop for food on the way from the airport. Then I remember the wine rack in the garage. I squeeze past the red Honda Jazz with black leather seats my father bought new and never drove. He used the money my mother had inherited from her own mother to buy the car, just as the doctor insisted that he should give up his licence. I make a mental note to put the battery on charge. There's a thin film of dust on the paintwork, thicker dust on the wine bottles and on the golf clubs in their bag, leaning against the rack. I take two bottles back to the kitchen in the hope of finding one that isn't oxidized, but I have to empty both down the sink. There's some whisky, so I pour myself a shot and add a little water.

This bungalow was never the family home. When my parents moved here in their retirement, my sister and I were long gone, with lives of our own. There are only one or two memories that attach to the things in it: a gadget for opening the lids of jam jars I noticed just now in the kitchen drawer, for example. Its gears

and extending lever fascinated me as a boy. There is a wooden pestle and mortar, ornamental and never used. The old Sinatra records have gone, along with the record player. No more *Pennies from Heaven* with Frank and Count Basie on the cover. The cheap plaster bust of JFK, its chipped shoulder glued but showing the crack, and the hardback copy of James Joyce's *Ulysses*, one of the two books my father owned – the other was Leon Uris's *Trinity* – those things have gone too, who knows where.

I feel a quite irrational irritation that there is so little here for me to remember. Those missing objects would have helped me feel more connected to this house, to my parents, and to the unfolding drama that has dragged me back into their lives. My relationship with our shared past, and indeed much of my own past, is one of a man waking from a dream, events fading as fast as my eyes blink open, leaving only mirages, a vague atmosphere, an emotion untethered from any coherent narrative. The mind is a wonderful instrument, but my memory makes only a childish collage of all that actually happened, and does so with scant regard for the truth. So little survives intact through all their many house moves and their shift to another continent.

My parents emigrated to America on my eighteenth birthday, the day after Elvis Presley died. I refused to go with them. I said America was a heathen land – to

my shame, those were my exact words – with no social security system worth talking about and no health system fit for purpose. My father wanted me to study business. I told him I would study English literature, in England, because I wanted to be a writer. He didn't laugh in my face, but he did make it clear he would not give me a penny in support. I said that was fine by me. For a long time, we only saw each other for brief holidays. Things were better like that.

My sister was only sixteen when they left and was too young to see the move as anything but an adventure. We were always close, though we had separate lives, and we would keep that closeness through the years to come, despite living on different continents. She had just completed her O levels, and she went straight into an American high school the likes of which she had only seen in movies such as *Grease*. I went to university in Kent, and immersed myself in modern poetry and philosophy, beer and marijuana. Meanwhile, my sister, made exotic with her English accent, was dating a star of the school football team. She didn't fight with my father as I had as a teenager, perhaps because, as his daughter, she escaped his desire to mould her in his image. It was enough for him that she was happy to be with them in America, and settling well; so well that she would go on to make a life for herself there, and later in Canada.

They set up home in the suburbs of Washington, DC, where my father became general manager at National Airport, responsible for the company's operations. My mother found part-time work at the local county offices. She had always worked, as well as being a wife and mother, for as long as I could remember. But when, more than a decade after going to America, my father's career ended in the ignominy of demotion and redundancy, he and my mother sold, or gave away, everything they owned, including our old Labrador, and limped back to the UK. It was 1989. They were in their late fifties, and if my mother was happy to be closer to her mother and to me, my father was a defeated man. His American dream had been shattered. He suffered a nervous collapse and a severe depression that left him bedridden for a year or more. That was the first time he took to his bed. Unable to come to terms with what had happened, or to see that some things in life are mere accident, he turned his bitterness and disappointment on his family and friends, but especially on his wife.

When my mother was diagnosed with Parkinson's dementia, his depression turned to anger. What went on behind closed doors showed itself from time to time and was repellent, though there was little I could do about the petty cruelties, mad rages and anxiety attacks, other than learn to protect my mother as best I could. The golf club might have been a refuge for him, but in latter

times his treatment of my mother came to the attention of other members and made it hard for him to find playing partners. Family gatherings were excruciating. I remember an occasion when I met my parents at a pub with my daughters, who were young at the time. My father insulted my mother repeatedly, telling her she was useless to him and a burden. I said I would not have my children listen to such talk and we started to leave, but my mother begged me to stay, fearing the consequences of being alone with him when he was so angry.

As her dementia progressed, he justified locking her in her room as it being for her own safety. He banned friends and family from seeing her. He point-blank refused to allow anyone to look after her in order to give them both a break, even for a weekend. He needed the burden of her care to explain his own misery. I forced the issue when I could, spending hours on the phone persuading, demanding, pleading, and from time to time I won a brief respite for her, and I suppose for him.

On the few occasions she was permitted to come and stay for a weekend – Marie and I were living together by then – we worked hard to convince her she'd be safe with us. I even went so far as to suggest we set up home, just the two of us, Mum and me. Even through the haze of dementia, she knew all of this was too little too late. They were locked together according to their vows and in a bond none of us could really fathom. I remember

one time when she was staying with us and we'd said everything we could say, she asked in a small voice if she could please phone him. She didn't like the idea of his being alone.

My mother may have been his prime victim, but she could also be his protector. Sometimes she would tell me quite firmly to leave things alone. She told me that anything I did would only make him worse, and that if I wanted to help, I should be nice to him. When my sister began to upbraid him for his actions, my mother told her not to interfere with her marriage, and did so with uncharacteristic anger, leaving my sister upset and at a loss. It was simply not in my mother's nature to condemn her own husband to others. She could not do it. There was little we could do to help. I tried many times and failed. And so it went on, for years and years.

It was here in this bungalow that I first organized carers for Mum. My father hated them coming into 'his' home, I suspect because he knew that now there would be eyes on him. The carers came three times a day to look after her, and I began to hope there might at last be some peace of mind. Instead, there were reports of suspicious bruising on Mum's arms, probably from my father's rough handling of her, and when word got back to him, he would no longer allow them to wash her.

Social services attempted to intervene. Mum was

put on the 'at risk' register. Brenda, the head of the care agency, tried gentle persuasion over coffee, and went above and beyond to effect some kind of change in him. But the charm he'd used as currency all his life let him get away with it, to begin with. He was always plausible, often fawning, especially with professionals. It became shockingly clear to me that in the eyes of the law, husband and wife have inviolable rights over one another's welfare, and that the law struggles to assert itself in such situations.

I tried to get him counselling. I booked and paid for sessions. I remember waiting in the road outside their bungalow to take him to the therapist. He refused to come out and was stratospherically angry.

My mother would sometimes call me. But only if he was out of the house. We would run through the same script as always: me urging her to leave him, she resisting, the conversation truncated by his return, my mother fearful at the sound of the door opening, a click as the receiver went down, and the sound of the dialling tone.

I need a cigarette, so I open the conservatory doors to the wintry garden. The frost is hardening and the branches are bare. In the darkness beyond, I get the sense that the trees and hedges are unnaturally still. I have to focus. I am here to sort things out, to find a hospice where my

father can see out his last days, to sell the house, clear the debts that have no doubt mounted up and, when the time comes, organize his funeral. The paperwork and the arrangements will take several weeks, maybe a couple of months. My father could last longer, because all that is truly wrong with him is that he has stopped eating and is wasting away. Still, I can return to France and let the professionals at the hospice take care of him. I can visit my mother from time to time, as I've done until now. I can keep my sister, who is six thousand miles away in Canada, up to date, and I can get on with my own life.

But even as I tell myself all this, I know there is a choice. I assisted the authorities in removing my mother from her home because I loved her and wanted to protect her from my father. I still love my mother and I still want to protect her. That hasn't changed. No one will blame me for returning to France and leaving her in the care home, but I don't have to go back. I have no full-time job, no home to pay for, no partner to object, and both my daughters have lives of their own. Phil can build his house without me. The book I am working on could just as well be written here.

Though I have no idea how to go about it or who to ask, or even if it is possible at all, it's clear that when my father dies, I could bring my mother home. I flick my cigarette butt into the darkness and close the doors on

the freezing night air. I am free to choose, but no one else can make this decision for me.