

Supporting Carers of Older People

VIGNETTE

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Vignette - Rosa

You are a GP contemplating to whom and what to include in referrals for Rosa, a patient you've been seeing for approximately three years. Rosa started attending appointments with Phil (her husband and also your patient) shortly after his diagnosis of dementia (Alzheimer's disease) three years ago. You had assumed that she attended as Phil's carer, a role she took on when he was diagnosed but you've just learnt that Rosa does not have her own GP. It dawns on you that Rosa has 'lost herself' in her caring role. Hopefully you have 'found' her in the nick of time.

You reflect on what you know about Rosa and her situation:

Italian born Rosa (76 years old) and Irish Phil (78 years old) met in London as university students. They married in 1967 and immigrated to Australia. In 1971, they welcomed their only child Francesca (49 years old). Francesca and her husband have a daughter named Rose, Rosa's granddaughter (17 years old).

You've been seeing Phil for around fifteen years and you know him to be a tall, physically imposing man with a shy, timid demeanour. While he was still employed he was immersed in (almost to the point of being obsessed with)

his work as a professor in the engineering department of a major university. Upon receiving a dementia (Alzheimer's disease) diagnosis three years ago he retired and Rosa formally assumed the role of his carer. Since retirement, he has become increasingly withdrawn and vacant.

Rosa is slight in stature but usually big in presence, an engaged and engaging woman who has always liked to keep busy. She was significantly involved in supporting Phil's role at the university (he'd refer to her as '*my personal assistant*'). After his retirement she kept busy with weekly U3A (University of the Third Age) classes, hydrotherapy classes, bridge group, cooking for Nellie (a neighbour who had recently lost her husband), gardening and quality time with her daughter and granddaughter.

Except for high blood pressure, prior to the onset of his dementia symptoms, Phil enjoyed relatively good health. He attended your clinic as required, which wasn't often.

However, his dementia symptoms swiftly escalated. You notice his increasing reliance on Rosa (even to find his way around the waiting room at the surgery and recently he became disorientated going to the bathroom). His expressive speech is rarely spontaneous - when he does speak it is of years gone by

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when he was working and he tends to be repetitive. He lets Rosa take the lead and answer all questions put to him in your consultations. His verbal comprehension is impaired. Cognitive screening with the Montreal Cognitive Assessment (MoCA) revealed a score of 16/30.

You've not heard Rosa or Phil complain nor do they appear worried about their situation. Aside from occasional references Rosa makes that her '*precious garden*' has taken second place to Phil, she consistently promotes that all is well at home and that she and Phil are '*coping just fine*'. Similarly, Phil often states '*Rosa will look after me. She always has*'.

About 12 months ago Rosa commented that Phil tended to '*wander I no longer can trust him to be alone. I must supervise him to keep him safe*', providing insights for you of the situation at home. You suggested that Rosa and Phil consider an Aged Care Assessment Team (ACAT) assessment but Rosa wouldn't consider it '*we are good, thank you. I'm perfectly capable of looking after my husband. I gave up my classes to do so*'. You sensed you might have offended Rosa as you felt her tense up and heard a brittleness in her response that you hadn't heard before.

Francesca, her husband and their daughter, Rose, live in a neighbouring suburb. Rosa and Francesca have a close relationship and they'd see each other regularly – spending large chunks of the day together – Rosa helping Francesca around her house and vice versa. If

they weren't at home they'd be out shopping together '*Francesca loves shopping! Me? Not so much, but I like to see her happy*'. At the beginning of this year, Rosa tells you '*that Francesca needs some space from me. She wants to focus on Rose. She's doing her final year at school. It's a big year for them. They don't need me..... the good thing is it frees me up to look after Phil*'.

Since you made the ACAT referral suggestion Rosa tends to over engage with positivity and reassurance '*I don't want you to worry. I don't want Phil to worry. No one needs to worry. Everything is under control*'. However her presentation belies her talk. Over the last year you note that Rosa seems to becoming '*smaller*' she has lost weight, consistently looks tired and her personal care (clothing, hair, body odour) appears neglected.

In Phil's last appointment Rosa enters your room limping. When you comment on her gait she tells you she tripped over Phil's loyal companion dog, who at age 16 is slow to move and rather deaf '*it's made my wonky knee worse. I've got osteoarthritis and I used to get some physical therapies for it. But I haven't for a while. And now that it's flared up again I can't de-clutter the home. We don't need Phil's papers and books lying around anymore. Nellie told me that she'd come to help me because she's worried that one of us will trip over. It's such a big job, but I told her, don't worry I can look after it. I mean Doctor why does she have to put herself out? She's got better things to do*'.

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When Rosa showed you her inflamed knee you asked her what course of action her GP had prescribed. You were somewhat taken aback when she informs you that you are her GP.

You are struck by how your observation about Rosa's gait has made you privy to a range of concerning issues (about Phil and Rosa as patient and carer but also as individuals struggling with ageing related health issues) of which you were previously unaware. You make a note to follow up about trip hazards around the home but for the moment are prioritising engaging Rosa in the health care she needs.

You arrange an X-ray for her knee and a follow-up appointment to discuss the results. The X-ray indicates significant deterioration of the knee joint for which orthopaedic intervention will be required. Rosa quickly becomes very distressed and that brittleness, which is more and more a feature of her communications reappears *'well I don't know when I'll have the time to see the surgeon. I can't leave Phil. The surgeon will just have to wait. I can still walk for goodness sake!'*