“I want them to remember their father, not the dementia”

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In 2003 there were 2.5 million Australian carers of whom:

* 18% (452,300) were aged 65 years and over (Australian Bureau of Statistics, 2008) and
* 83% of older carers are caring for a spouse (ABS, 2008).

Many of these carers face a time when their spouse is admitted to long term aged care, frequently when their spouse has dementia.
This is part of my PhD study that aimed to identify the lived experiences of the carer after their spouse’s admission for permanent care. Participants were interviewed by the researcher up to 3 times in the first 12 months after admission of their spouse. Open, unstructured interviews were used to encourage the participant to raise what was important to them at the time. Interviews were audio recorded and transcribed verbatim. They have then be read and re-read by me, the researcher, whilst listening to the initial recording to obtain as much information as possible.
P7 has two daughters and a son.
P7 was violently attacked at home by her husband resulting in his hand around her throat and a knife in his hand.
This was the ‘final straw’ for the decision to admit her husband into full time care in a dementia unit.
P7 does not share her thoughts with her children so they don’t understand why she is still not caring for their father at home.
She “wants them to remember their father, not what the dementia has done to him”
* P8 has 2 daughters. Spouse is 58yo.

* I don’t want to do it to them (ask for help)...they still say but that's Dad, I say well it’s not Dad anymore. The disease has made him something else.

* I’m too old to make friends....everyone’s set in their own ways.
* Not using family for support

* Family just don’t understand. - it’s very different to them. They have their own life. (P10)

* Isolation

* It’s very lonely-very...there’s nobody to talk to. There’s nobody else (P8)
* I’m too old to make friends....at this age everyone’s set in their ways
* I don’t know if there’s anything out there...I mean I have to start looking because I can’t carry on
Guilt.

After travelling and being away I went straight in to see (her husband). One of the nurses said “oh, we haven't seen you for a while”. I immediately felt guilt, as if I had something tattooed across my forehead that I didn’t care (P10).

Even an innocent comment can cause me lots of guilt.
Family centred care

* A culture of proactive support to spouse and family
* Do not judge when family members do not visit.
* Provide support when family members do visit.
* Educate the spouse: although the dementia is more apparent, the person, their emotions and feelings are still there.

A big challenge for staff, spouse and family.
*I want them to remember their father not the dementia*

Whilst a parent tries to “protect” their children from the realities of dementia effects on their other parent, they may be causing more damage to themselves, leading to significant isolation and continuing guilt.

As healthcare providers we must assist in supporting the parent, and child/ren with understanding, support and education as needed.

Serious consideration needs to be given about formal support to the spouse of the person who is receiving care.

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