

Dr. Jane Youell

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How do people living with dementia and their carers experience and understand the changes in intimacy that accompany living with dementia

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PhD Summary - Participants



21 carers



10 people with
a diagnosis of
dementia

Research Summary

What did I find?

- There's no place like home
- Let's talk about sex
- Renegotiating relationships



Sex

And why it's good for you.....top ten

- Helps keep your immune function healthy
- Boosts your libido
- Improves women's bladder control
- Lowers blood pressure
- Eases stress and tension
- Good exercise
- Good for your heart
- Lessens pain
- Improves sleep
- Increases sense of wellbeing



Sex

And older people.....

- Old people don't have sex
- People who are ill don't have sex
- Therefore, old ill people definitely don't have sex

Byer/Shainberg/Galliano *Dimensions Of Human Sexuality*, 5e. Copyright © 1999. The McGraw-Hill Companies, Inc. All Rights Reserved.

% of People Still Sexually Active with Partners by Age

PERCENTAGE OF PEOPLE STILL SEXUALLY ACTIVE WITH PARTNERS, BY AGE

SEXUALLY ACTIVE WITH PARTNERS		
<i>Age</i>	<i>Women</i>	<i>Men</i>
70-74	30%	65%
75-79	22%	53%
80-84	9%	48%

Source: Data from E. Laumann, J. Gagnon, R Michael, and S Michaels *The Social Organization of Sexuality* (Chicago University of Chicago Press, 1994).

Lets talk about sex

“You didn’t ask me too many intimate details because I don’t think it’s necessary. Sex is sex.” (Lily)

“Absolutely and I think what happens in our relationships is its much more about holding hands and cuddling” (Jane)

“It does come to that eventually but I think we had a jolly good run is all that I can say. I mean I’m no glamour puss and he’s not either but by Jove we did enjoy it. I mean I can say this to you because you’re doing this, I nearly said to my daughter-in-law yesterday and I thought Oh God be quiet, this morning I was saying something – that you were coming – and I thought no, be quiet. I don’t think she’d be....see this....as quite the thing (Lily)



That's not Leonard! – sexual identities and dementia

I suppose I never got over the fact
of finding him getting dressed up in
a ladies clothing in the bedroom, a
wig on, makeup, high heels
I.....that wasn't Leonard (Emily)

I've caught him dressing up, oh
right, put it behind you, don't say
anything, but having to keep all
these secrets isn't easy (Emily)



That's what I miss....

“Yes, we both wanted the kisses but, of course, as I say we couldn't go any farther than that, then of course when she fell off, when she fell and couldn't come back up again, we were both sleeping together on the same bed to start with and then of course the carers couldn't lean over and sort her out and this is why we had to get rid of the original bed...”(Ronnie)



That's what I miss....

“And how did that feel for you?” (Jane)

“Terrible. That’s the one thing I miss, is having a nice warm, forget the sex business, to have a nice warm body to cuddle at the side of me. That’s what I miss, I’d love to have another nice warm body so we can have a kiss and a cuddle, forget the sex again, forget that, but to have a nice warm body to just go lie at the side of, or back or whatever, just to miss having that kiss and cuddle to go to sleep on, I miss that.” (Ronnie)



That's what I miss.....

It was, fortunately it had been changed that week and as I say he never, ever wet the bed and I can't change his bed and I go [getting teary] in ever night and lay in it and talk to him and this is what people don't understand you're still living, you're still living that awful loss the whole time it's not just you go in and see them and leave them, it's hard for people to understand that you're grieving the whole time (Betty)



Can't say no – consent, capacity and complexity

Well I would say that Maggie's more, she appreciates it more now than she did years ago, so I don't see any change, other than she seems to enjoy it more but I think that's because she's relaxed and has no inhibition in any way. But otherwise it hasn't changed in any other way either in frequency or intensity but I think it's a little more intense now I think (Geoff)



Sex and consent

Is it still ok?

the last time we had sex was on holiday three years ago that doesn't mean that in the months following that I didn't try to have sex. I'm still viable despite what young people think....

But either I got the feeling that I mean the desire for sex had gone and I always tried to give as much pleasure as I got and when I didn't see the pleasure exhibited and then if I petted her she would find it funny she wasn't sure why I was doing it so it's like if you can imagine you're trying to be romantic and your partner laughs it's not exactly conducive to romance and that it went from disinterest to what are you doing to stop it and so I think I probably made some effort for a year or so after we had sex the last time (Martin)





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