

## The context of caregiving for family members / friends towards the end of life

### I'm not a carer

B: "Yeah, I never thought about being a carer."

L: "You feel that you're doing your duty, don't you, really? I didn't really class myself as a carer."

B: "You just do it."

**I was his wife** "I wasn't really his carer, I was his wife. I mean to me a carer is a person who maybe has a relationship with the person who they're looking after, but they're not like husband/wife, son/daughter, sort of thing. [...] that's something, you know, in sickness and in health until death us do part, it's part of what you sign up for."

### Not knowing

"Of course, the district nurse does that, and then she gets in touch with this nurse. And then the practice nurse comes from so and so and you think, yeah, but you all know that. This is all new to me. It doesn't make any sense to me. You're telling me as if I should realise."

"You don't know what you don't know."

### Doorstep conversations



"I think I would have liked if they... When we'd seen [wife], come down and sit down and have a consultation with me. And although they always asked, it was more like, as they went out the door. Sometimes it was a long conversation on the doorstep."

### You can be both

"So I think probably at the very start it would be very helpful for people looking after those who are critically ill to understand, for your own sake, whether you like the term or not, it's really important to understand that's who you are because then when you come to fill in your forms and your allowances or whatever it is, whether it be financial or what have you, then you are in a position to say actually, I am my husband's wife but I am in the position of carer as well."

### A Key

"Once you've got that word 'carer' that's a key they put in your hand and that word enables you to click on sites, fill in forms, tick boxes."



### Wanting to do it all yourself

"Because you don't know from the beginning how you're going to react, and you don't know what you're going to need, 100 percent. But as time goes by, you realise you need something here, something...everybody likes to feel they can do it themselves, but then you come to realise that you can't do everything yourself."

### 'How are you?'

"I think really they could have spoken to you more, asked you more, if you understand what I'm saying there. It's just, 'how are you?' 'Are you alright?' And...I'm one of these people who'll say, 'Yeah, I'm fine.' "