



Transcript:

[Watching a home video]

Jim: This is err Jan and I in Italy in 1996, it was our first trip to Italy err...

Narrator: ...Jim and Janet Swift loved travel. The two teachers from Bolton went all over Europe and Jim's memories of this Italian holiday are happy ones until the day after they had taken this video in Venice.

Jim: So this is Jan looking casual, its erm the day before er Jan frightened me to death by saying that she couldn't remember this day. We went out for a meal one evening, stopped at a bar on the way back and whilst we were there, Jan suddenly turned to me to say where did we go yesterday, and it was the terror in her eyes. It wasn't just sort of a loss of memory, she was really frightened. Do you remember the girls going into St Mark's were told...

Jan: Yes.

Jim: ... to cover their legs.

Jan: mm.

Jim: Come a bit closer then, give me your hand. Remember the white hat.

Jan: Yes, it was.

Jim: Who is that? It's Sophie Loren, no it's not its you.

Jan: [Coughs] yeah.

Narrator: Today Janet can hardly remember she even went. Early onset Alzheimer's disease robbed Janet of her career and the future that she and Jim had planned together.

Jim: Was from the camera...the affect on er the family has been devastating. Er, it has been called a living bereavement, it's not the retirement either of us had planned. Before you retired, you got very old, what did you do?

Jan: Going dem

Jim: When you were working?

Jan: You were, were working to to ya.

Jim: I say, teacher.

Jan: Yes.

Narrator: Janet Swift was a successful teacher and Headteacher.

Jim: She was caring, fantastic teacher, well organised and now her mental abilities are less than the children she taught which were mainly er infants and juniors.

Narrator: Fearing that his wife might have dementia, Jim got Janet to a doctor who referred her to a psychiatrist.

Jim: Originally he said it was depression but eventually he sent Jan for a scan. The scan showed a perfectly normal brain. I had been keeping from Jan my fears, er but now I have explained to her what had been going on and she said, well I'm glad you hadn't told because I wouldn't have wanted to know.

Narrator: Despite what appeared to be good news, Jim's private fears persisted. Things didn't get any better. Janet started to double book herself at some schools or simply not show up at others.

Jim: I remember on one in instance had sort of fourteen tins of tuna because Jan obviously couldn't remember if she had bought any on the previous visit to the shops.

Narrator: A second scan confirmed Alzheimer's disease. Janet was fifty eight years old. Today she does not know what's happened to her and Jim has never told her that she has dementia.

Jim: So it has been difficult because we've not been able to cry together and I've still had to be the same silly idiot I've always been in her eyes. When you first get the diagnosis, you are at a loss as to where to go, who to turn to.

[Door Bell Rings]

Jim: I think that maybe Paula.

Narrator: Twice a month Paula Smith, an admiral nurse visits Jim...

Jim: Hiya Paul, come in.

Narrator: ...to advise him on organising the care Janet now needs.

Jim: I'll just lock the door. Erm she told me that the disability living allowance, er how to claim that. Er she told me about the agencies er that I could get to provide support, so she has been the person to guide me through.

[Background chat]

Jim: Pass your cup.

Paula: How you doing?

Jan: Oh I'm getting warmed up, I've got me me shoes, me shoes.

Jim: She's got her new outfit on.

Paula: Lovely.

Jim: It's her birthday on the fifteenth.

Narrator: But there are fewer than seventy such specialist nurses across the country and not all carers maybe able to get access to one.

Paula: Apple Nurses are a team of specialist nurses who support carers and family carers of people who are experiencing dementia. We are usually employed within a mental health trust erm within the NHS and we except referrals from both family carers, from friends, from GP's, from the consultants and th...the hospital teams, erm and that's usually how we become engaged with p...with our carers.

Narrator: People with dementia may exhibit mood swings and varying degrees of aggression making life hard for their carers. Jim needs advice on how to handle his wife's increasingly unpredictable behaviour.

Jim: Not nice to be told your nasty and horrible and um...

Paula: No.

Jim: ...stupid.

Paula: I think a...another good coping strategy would maybe because I know Jan and you both enjoy music, maybe to have some music playing in the background...

Jim: Yeah.

Paula: ...while, while your you know helping her to get ready in the morning.

Jim: Right, I did get from the day centre, apparently Jan dances to a particular record so I've borrowed the CD and copied it, and er it's like Pavlov's dog she'll get up, put the music on she gets up and dances so er.

Paula: Right, that's really good... Erm our role is primarily in, in focused in supporting the carer of a person with dementia rather than the person with dementia them self. We are all me...RMN's, were all mental health nurses. We've recently applied for direct payments which have been successful in receiving these.

Jim: Yeah.

Narrator: Paula has helped Jim get direct payments so he can decide what's best in his situation. Three days a week he sends Janet to a day centre, allowing him what's crucial for all carers, time to themselves. Although this time apart can be difficult to come to terms with.

Jim: Erm, well restbite I found difficult because I was sending Jan into a situation where I was aware that she could be unhappy and I was still doing it.

Paula: Sure, sure.

Jim: But you persuaded me and I agree I needed it.

Paula: I think for both of you it's important.

Jim: Yeah.

Paula: You both need a little bit of a break from each other.

Narrator: Jim took early retirement from teaching and used his life savings to convert their home to make it easier to care for his wife. As Janet's condition has worsened, Jim's sister Audrina regularly helps look after her.

Jim: Jan has found it...

Paula: Mm

Jim: ... difficult [mm] showering [mm] but now that we've got the erm walk in shower...

Paula: Sure.

Jim: ...and with my sister there, that sort of helps. We can persuade her, better than I or to get her into the shower.

Paula: So, do you do it together or?

Jim: We do it together, yes.

Paula: Oh, that's good.

Narrator: Paula also advised Jim how to organise carers who can help look after Janet at home and allow Jim some time to himself.

[Chat in the background]

Jim: Once the carers have left, you are by yourself again with your wife.

Carer: See you on Friday.

Jim: Yeah.

Carer: Yeah.

Jim: Thanks for doing Jan's hair.

Carer: No problem.

Jim: Okay.

Carer: Bye.

Jim: Bye... and you have to do everything. So you are alone, my wife doesn't converse much. She can understand me talking to her even watching the TV unless it's a comedy program she is unable to interact with it, she can't follow the plot and so basically you are alone... Err last time I picked her up from Firwood, last Thursday... Now were at the stage where basically all we have left is the fact that she recognises me and other family members and also that she's still aware that she loves me.

Jan: [unclear-00:08:03]

Jim: This morning do you remember Audrina come.

Jan: Come round?

Jim: Mm

Jan: I didn't know that.

Jim: But even the fact that she recognises me disappears, er several times a day now she will look at me and say where is Jim? Er, she will say I want to go home, er and I'll say well we are in our house. So, bit by bit everything is stripped away, er until you have very little of your wife left.

Narrator: Looking after a spouse with dementia is difficult. Providing support to a carer is greatly helped by an admiral nurse if there is one in the area. Everyone involved in care and support must remember that the carer may well need time away from the person with dementia to maintain their own ability to cope.

Jim: Is that better?

Jan: Yes.

Jim: Okay...Jan was the love of my life, she's a new Jan now but she's still the love of my life and my aim is to make everyday a Christmas day for Jan to make her life as golden as possible in the short time that we have left.

[End of Recording]