Narrator:
00:00:21 What does it feel like to live with dementia? The experience of living with dementia is often a challenging one. The more people’s emotions and perspectives are understood, the better they can be supported. This film introduces four people who are able to share their insights on living with advancing dementia, insights that were filmed over time, and which were not always easily communicated.

Barry:
00:00:49 I wake up and I feel afraid to get out, what am I going to face today, what’s going to go wrong. Because I’ve always got this thing in my, well, often get this thing in my mind to say, you’ve done something, you’ve broken something, you’ve lost something, you aren’t any good to anybody, why are you here, I get that a lot.

Olive:
00:01:07 Oh it’s awful. You get to the stage where you don’t want to talk to people in case you repeat yourself.

Judy:
00:01:20 I couldn’t go outside and go to a shop or something, I’d die, well I couldn’t do it.

Bob:
00:01:37 I used to do alright one time, but it seems to get a bit harder and harder every year. You end up with things like this.
Olive:
00:01:58 Well you don't feel as if you are in the world. At least I didn’t. I didn't feel as if I was part of the world.

Judy:
00:02:06 Yeah, I used to have fun.

Barry:
00:02:19 It makes you feel defeated. What good am I in this world, I'm doing nothing. More than sit down here and be fed and sleep, washed and, like an animal.

Judy:
00:02:31 Let me live.

Narrator:
00:02:37 Barry has lived with dementia for more than fifteen years. He is aware of the changes within his life and is still both able to articulate this, and importantly, express how he feels about it.

Barry:
00:02:49 Well when I came home last night, and I went out Ange said she wanted a cup of tea and I said well I'll make that one minute. So I went out and made the tea, but I couldn’t remember which cupboard was which, couldn’t remember where the jam goes, where the sugar goes, where’s the milk, where’s that. And I was like this for a minute or two, is this my kitchen? I used to manage butcher’s shops, I used to run a care home. I used to drive all over the country giving lectures on meat, here I am, I can’t make a cup of tea.

Narrator:
00:03:16 Olive, who has lived in a care home for two years, describes her feelings about dementia.

Olive:
Awful. It’s terrible. Because you’re hurting the people you love most, dementia. You really are. It makes you feel very guilty.

Narrator:

Bob has received full time care for two years. He talks about how dementia has changed his life.

Bob:

In a word, concentrating. I can’t seem to concentrate on one thing for very long. I don’t think you realise how it hits you.

Narrator:

Bob’s symptoms include hallucinations and mistaken beliefs, which his wife Sally explains.

Sally:

When he gets hallucinations, they’re extremely real to him. He sees things that aren’t actually happening. We’ve had problems where his room’s been on fire, and he’s had to get out.

Narrator:

Shortly before Bob moved into a care home, there were two occasions when he found himself on the roof of his house.

Bob:

Twice I got up on a roof, walked across the roof of a house. I don’t know what made me do it. That’s the difficult part, you can’t explain it. All you can say is it’s happened, and you did it. One o’clock in the morning, it’s quite frightening.

Narrator:

Judy was diagnosed with dementia eleven years ago. She experiences problems with visual perception and is often disorientated.
Judy:

00:05:10 Where am I here? I know who I am, I’ve got that one down.

Karen - off camera:

Where are you here?

Judy:

Yes, no, what place is this place?

Narrator:

00:05:12 Judy’s daughter Karen knows her mother so well that she understands Judy’s needs and feelings even when Judy can’t find the words.

Karen:

00:05:20 She wants to express herself in ways that she just can’t anymore. She wants to do things that she just can’t do anymore. But because she still has a little bit of insight, it makes it really difficult because she still knows the things she wants to do, but she just can’t do them.

Karen:

Why are you sad mum?

Judy:

Looking back, looking back.

Karen:

Looking back?

Judy:

Yeah.

Karen:

Why does it make you sad looking back?

Judy:

Oh, I don’t know. Probably I should’ve done other things. Just, you can’t do anything about it, that’s the thing.

Narrator:

00:06:16 People can feel powerless in the face of dementia.
Bob:

00:06:20 Well, it’s like a silent illness isn’t it. It’s the sort of thing that creeps up on you. Yeah, there is a feeling of loneliness.

Barry:

00:06:29 Well, dementia stole in. I had no understanding that there was coming this thing that was going to attack my mind. I had no idea that anything could attack my mind if you know what I mean. Other people yes, but not me, didn’t occur to me that it could happen to me. And it’s just like a persistent spy almost, someone who is not recognisable. But his effects are, what he leaves behind him and what he’s implanted, are noticeable.

Narrator:

00:07:07 Dementia is sometimes portrayed as taking away a person’s identity. Judy was asked if she feels this is true for her.

Judy:

00:07:15 Oh, doesn’t, you are what you are, well that, well with me, I’d be the same, exactly the same as I am. I’m sorry, it’s still me, it’s still me. I’m the same.

Karen:

00:07:35 It’s horrible, because she was so young being diagnosed with Alzheimer’s, but then you know bits of her do still shine through and she still is my mum.

Narrator:

00:07:47 Barry is also clear on this point.

Barry:

00:07:49 Yeah, I’m a man, it’s me. And I am me, I’m my wife’s husband, I’m my son’s dad. And it seems to me that most people, ‘oh she’s got dementia’ that’s
sort of like a full stop. End of sentence, end of discussion, 'she’s got dementia’ or ‘he’s senile’.

Narrator:
00:08:09 Supportive relationships with families, friends and professional carers play a key role in helping people with dementia live well.

Olive:
00:08:17 They’re very caring, and I get big hugs from my husband, my children. And ‘that’s alright mum, you forgot something, that’s all, doesn’t matter, here we are’. And it’s all sorted out again. (laughs)

Judy:
00:08:33 Well, to stay here and help, help me. Just as to be.

Bob:
00:08:45 Always been friends as well.

Sally:
00:08:46 Yeah. Friends before the romance, so I think then you do stay in a loving relationship because the depth is there, isn’t it. But he’s still the Bob I fell in love with, and I still love, he’s still that person underneath everything.

Narrator:
00:08:59 For people with dementia, as with any individuals, empathy and support can help to retain their sense of identity as well as enhance their wellbeing and quality of life.

Karen:
00:09:11 If I could say one thing to somebody who’s got dementia or a carer, it would be probably, hang on in there, because they really do need you and they have feelings and totally understand what you’re saying. And one thing, if I walk into the room and Mum can’t see me, she hears my voice within a split second if I say hello to somebody, she knows that I’m there, and it means so much to them.
(to Judy) Hello.

Judy: Hello (laughs)

Title: Key learning points

People living with dementia can still be alert and aware of their condition.

It is important to get to know the person with advancing dementia as an individual and support them to maintain their identity.

Although dementia causes the lose of some abilities, people’s feelings remain intact – it is essential to respect and empathise with people’s emotions.

Caring and supportive relationships help people to cope with the difficult experience of living with advancing dementia.

END