cohesion®
connected digital health

Voices

CONNECTED CARING COMMUNITIES PROJECT

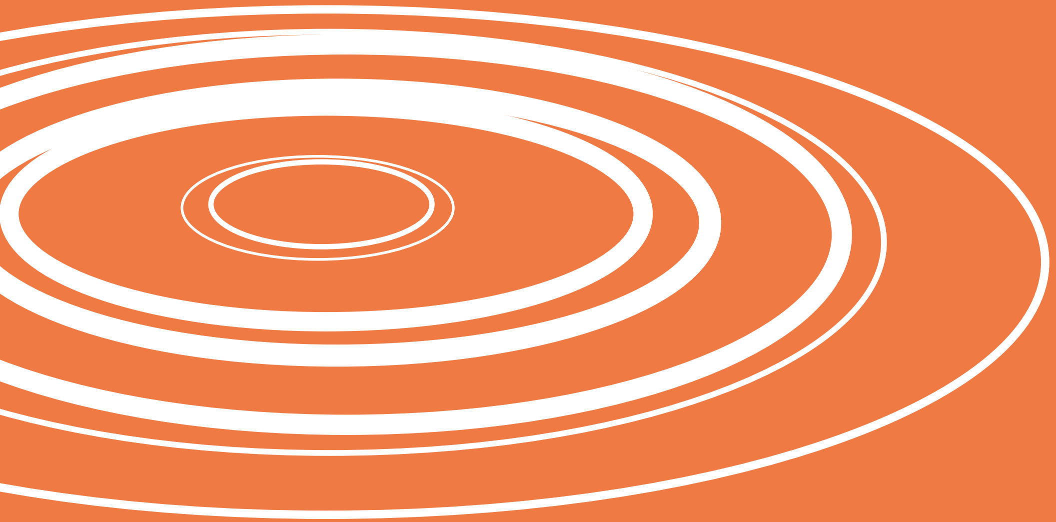
Listening to the voices of people sharing their journeys.

Voices of:

Ann
Nessie **Patricia** **Louise**
Fiona Sam Maureen Karen **Margaret**
Robert **Gail** Bill John H Christine
Ann P Jim Carol Jane **Paul**
Paul C John O'D Bill S

“*Dementia is a*

rippling pool.”



“I’m still me, I’m *still normal.*”

Jim

“Dementia is a *big societal problem.*”

Paul

“I want to *keep up to date* with the changes around me.”

Bill

“When you speak to other ladies, because the men have stopped driving, women are finding it so much more *difficult* and they all wish they had learned to drive.”

Carol

Christine

“Routine is good, or confusion can set in.”

◆

“I can tell when Bill is getting distressed or upset about things because our dog goes up and focusses on Bill.”

◆

“It’s just difficult, I feel guilty sometimes making these decisions, because I feel like I’m taking away things from him... but I have to do it.”

◆

“I want to alleviate Bills stress, but I don’t want mine to go up.”

> *‘You need to accept dementia and you will* **see it** *because if you don’t, it’s going to get worse.’*

> “*The population are all living longer. Dementia is the illness of our time. We just try to cope the best we can.... but it’s a downwards spiral. It really and truly is.*”

Maureen

“There’s no such a thing as a normal day. Nothing is normal.”

◆

“It’s a 24 hour a day job, it really is.”

◆

“My husband is one of the fortunate ones where he’s been diagnosed. What about the people who’ve not and maybe they don’t have the family there to help them?”

Jane

“It’s good to share your experience… And it’s also comforting to know that other people are going through similar things.”

◆

“Our mum had no mobility but I think that one of the huge problems for families with people who have got dementia, if they are mobile, is if you’re not there, you’re not watching them… they can just go walk about. That must be so stressful, and so difficult to deal with.”

◆

“That was a very sudden flip of how she was. From being our mum to being this lost and confused person very quickly.”

◆

“Although you kind of watch them decline, you sort of live for the moments where they recognise you and know who you are.”

◆

“You have to find humour in it just to cope with it all.”

◆

“Individually you’re mourning. You’re mourning the loss of somebody that you love who is still physically in front of you.”

> ‘*My main challenge is the* **time factor.**’

“Over on the mainland dementia is *more accepted,* because there is *more awareness,* and there is *more understanding* about it.”

Fiona

“*Things change* when you stop working.”

Sam

“The *lack of awareness* is huge.”

Louise

Gu math tric freagraidh e anns a' Ghàidhlig o chionn 's gur i a' chànan a bha e nas cleachdte ris bliadhnaichean mòr air ais.

I often find that he answers people in Gaelic because it is a language he spoke in the past, a long time ago.

John

"As a GP and a son I've found it quite difficult. When do you tell people they have dementia? How do you make the diagnosis? And how do you manage that process?"

◆

"It's a blurry idea and there's no real treatment, and I've always found it really hard telling people that."

John

“The four years we had up until now were mostly easy for us to deal with, but this year hasn’t been. This year, it has just taken a huge amount of my time. And you worry about it because you’re not sure you are doing the right thing all the time.”

•

“Until this year my mother would have never gone outside on her own. So, being able to talk to someone else who’s been through that, and ask “Right, what did you do? What kind of ways did you deal with it?” That would be useful.”

•

“Whenever my mum goes out of the flat, it’s a tiny difference between a neighbour seeing and helping her inside to her being able to walk a few hundred yards away and risk becoming lost.”

•

“It’s much better to have a social worker appointed to my mother because you’re dealing with a person, which is much better than just dealing with a faceless social work department where you might be talking to a different person each time you phone up and you’re having to have a very long explanation of all the background before you can actually get to what your specific request is.”

•

“I’m an only child, if I had lots of brothers and sisters they would share my mother’s care with me. It would be great to have other people who we could share it out....My mother needs lots and lots of hours each week where somebody needs to be with her and as an only child there’s not many people to share that with.”

“Sharing knowledge and information will help everyone realise *people are people.*”

Patricia

“Friends are aware of the problem but they don’t know how to react. This can result in them pretending that the person with dementia is not there… We need to combat this by *better education.*”

Ann

“I find I don’t have much *time to relax anymore.*”

Nessie

> *‘We begged them for a chair-lift as my mum was terrified of falling. She’d already had a fall. I felt they just didn’t listen.’*

‘Services are not good enough, everything feels ***broken.*** *Systems need to get better.’*

Gail

“The less you say, the more people think you are getting along fine.”

◆

“People who don’t have a large family network, find it is detrimental to their lives. The government needs to do something about it.”

“If you can’t stay *physically fit* it’s going to get hard for you.”

Bill

“Used to is a common phrase.... *used to do* a lot of things.”

Robert

“What we want is to *design the environment* to be an aid to a person with dementia.”

Margaret

‘*There should be*

no barriers.’

Paul

“Support services … this was a bloody nonsense and a total waste of time.”

◆

“Questions are process-driven, they do not ask about real-world or family life problems.”

◆

“These systems approach situations with a pre-determined answer. There are checkboxes of pre-determined answers for some support, or nothing.”

◆

“There are no formalised support mechanisms, no-one tells you anything of any value or use.”

“

If you don’t pursue things, you just …

fall

through the system.

”

Ann

“We cannot cure dementia but there are lots of things we can do to support it.”

◆

“If my family were unable to support me, then my community would need to support me.”

◆

“Being able to think things through helps Carers manage and understand.”

◆

“Dementia Friendly Communities can change culture and reduce the fear of dementia.”

◆

“If you can educate carers you can make the carer understand the illness and that it is not the individual that is the problem.”

“Carers need
tools &
training
in skills to
help them cope.”

With thanks to:

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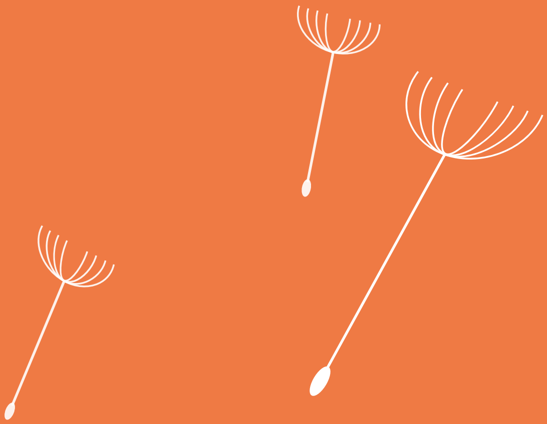

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Project supported by Life Changes Trust

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