



# PEN PORTRAITS

## A WINDOW ON LONELINESS AND ISOLATION IN ESSEX

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## SUPPORTING A WHOLE SYSTEM APPROACH TO ADDRESSING LONELINESS

ECC has begun an ambitious programme to galvanise system partners and local communities to help support those who are lonely and for whom this is a source of unhappiness. Work is underway to systematise a clearer pathway to identify, engage with, signpost and / or support people to establish or restore social networks. This will pick up those people who are presenting themselves to services (NHS, social care, voluntary sector) in some way.

Loneliness is deeply connected to social isolation; people can be lonely or socially isolated or both. There are not always clear, shared definitions of the terms which can be used interchangeably by people and professionals. In the interests of clarity, we are using the following definition of loneliness:

“a negative experience that involves painful feelings of not belonging and disconnectedness from others. It occurs when there is a discrepancy between the quantity and quality of social relationships that we want, and those that we have. Thus, loneliness is a subjective psychological perception.”

Hidden Citizens report, Campaign to End Loneliness

### Insight and Evidence

As part of the pre-insight and evidence gathering phase, RETHINK Partners with Healthwatch Essex Insight have compiled five pen portraits on people who are or have recently experienced loneliness in Essex. Some of their experiences have been profound, often due to major changes in their circumstances and lives. Others have been sporadic, but regular occurrences as part of daily life.

We were led by colleagues from Essex County Council adult social care team in our choice of the dominant characteristic of the people we were seeking to speak to. The connecting theme being that these characteristics are often shared by people who experience loneliness and who may not engage with statutory services, therefore limiting the opportunity for professionals to identify the issue.

### The people we spoke to, to create our pen portraits

- Sarah has a sensory impairment 3
- Helen is a carer 4
- John is recently retired 5
- James has learning disabilities 6
- Brian has a long-term condition 7

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## SARAH

Sarah is married and is in her early 40s. Sarah has a visual impairment and lives in south Essex.

I lost my sight two years ago as the result of a brain tumour and my social networks changed dramatically. This time, two and a half years ago I was an Assistant Head Teacher of a school and my life, and social circle - as it does in your 30s and you don't have children - revolved around that. When I lost my sight, my world disappeared. I lost my job, my career and my social network collapsed overnight. After such a life changing event, many people in your social circle are unsure about how to interact with you. I don't think it's as simple as 'you know who your true friends are', it's more that people are fearful. As a result, you become very reliant on family. This is why it was so crucial for me that social services put me in touch with an organisation that allowed me to meet other people like me and these new friends have become my lifeline.

The social activities are great and it's wonderful to be around people with a similar disability. It's not just about sharing knowledge and experience, especially around things like how technology can support, but it's about keeping each other sane. I'm part of an organisation that has some fantastic social activities. We have a weekly bowling team where we sit and take the piss out of one another. I now volunteer too.

Diagnosis is a key point in this journey and my relationship with my rehab worker was crucial in teaching me new things and helping me re-establish the foundations of my world.

Learning how to get the best out of tech has helped me keep in touch with those people I can no longer see, so although my social networks have altered greatly, I can still keep in touch with old friends through Facebook.

I'm young, but do have aging parents. I had expected to be able to look after them in their old age. My dad has now lost some of his sight too, but like me he has learned how to use all the visual impairment stuff on his phone and computer. In fact, even my husband does – which I tease him is a bit of a cheat!

I write the newsletter for the charity I volunteer for. I dictate it into my iPhone notes and take it from there. I meet lots of people my age who are in a similar position to me and we draw a lot of strength for one another. I also meet a lot of older visually impaired people and it's obvious that they are more vulnerable to those big life events, like losing someone as, naturally, you become very reliant on one person.



## HELEN

Helen is a full-time carer for her husband who has dementia.

I am Helen. I am 63 and have been married to Andrew for more than three decades. I moved to Essex to be with Andrew and we had a son and a daughter who now have their own children. I love being a grandmother. I also love gardening.

I gave up work and stayed at home to look after the kids and to be honest, Andrew's work took him away a lot so it made sense. He had a very senior job that meant a lot of international travel.

When Andrew became ill three years ago it was a shock. He's a strong man in every sense. And a proud man. I am his carer. It's an extremely full-time job because he is very dependent on me 24/7.

I am busy, I don't have any time to be 'lonely', as such, but there is a kind of loneliness you can feel when you are physically surrounded by people all day long.

Caring for someone with dementia is full of surprises. It's good to speak to other carers in the same position. My situation is that I can't leave Andrew. He would be too scared at this point, so respite care is not an option for us. We need opportunities where we can socialise together. They are my lifeline and I wish there were more, more frequently, near me. I need them to be very local. You see, when Andrew was well, he liked to drive. As a result, I've only been accustomed to driving locally: the school and supermarket run. And even if I were confident enough to drive further afield to a meeting with other carers and the people they care for in a neighbouring town, I don't actually think Andrew could tolerate the journey. It's very difficult.

I would love to be able to do more things outside of the house, but we are very limited as Andrew's disease declines and he struggles in most social situations. Facebook is a lifeline as is the internet in general. I am now a keen virtual gardener. I find my iPad useful because I can quickly switch it off when Andrew wants my attention. He can be jealous, even if it's me looking at another screen whilst we are watching TV together.



## JOHN

### John left a challenging career when he retired.

I think there are more opportunities for women to build networks than men. It depends on the person of course. I've always found it easy to make friends, but when I retired, I found myself suddenly without purpose and then without a reason to get out of bed. You think you're well-prepared for retirement, but it's like becoming a parent - the reality can be shocking.

I had quite a responsible job and to go from that to having no responsibility was tough. Then I also had a family situation that I thought I was going to be involved in and I wasn't. I attempted suicide. Like you often find, the family situation resolved itself and I moved back to Essex where I had lived previously, which allowed me to pick up old friends, make some new ones, and to help my daughter.

The big breakthrough for me was being introduced to the 'Men in Sheds' programme. I had looked at U3A, but wasn't attracted to it, then a friend of my daughter's who works in social services suggested Sheds. It's being around fellas like it used to be at work. Woodwork was a hobby of mine years ago, but I couldn't do it any more, because where I live now has no outside space.

It's given me purpose and I'm now a self-appointed ambassador, so I'm starting my own shed where it currently doesn't exist. This thing spreads by word of mouth and we have a wide range of men who come along now. Retired men mostly, but we also have a man in his early 40s who suffers from depression. People don't need to have any existing woodwork skills to join – in fact, not everyone wants to make stuff. Some just want to chat. Some are shy at first and stay on the periphery and have a cup of tea, then when they're ready, they join in.

We've located a free timber source. We never know quite what type or shape of wood is going to arrive, so it's always fun working out what we're going to build and sell. Chopping boards and boot pullers are popular and we just sold a walnut coffee table. One of our group is registered blind and is an ex production engineer, so he is able to optimize production for us. It's given him something to do and really, we all bring different skills – it's like a fully skilled factory.

Men in sheds has been amazing for me and we're trying to make itself sustaining and expand. For our expansion, we're setting up as a C.I.O.; we've found a location and agreed the rent. We're now setting up the shed, tools and insurance.



## JAMES

James is in his 50s, lives on his own and has a long term condition which affects his ability to work. James also has learning disabilities which means he struggles to read and write.

I've lived on my own twice. The first time was in London and it didn't work out so well. I had parties with people who I thought were my friends, but I realised they weren't my real friends. I came up to Essex and moved in with my step-mum for a while. I've been living in sheltered accommodation in Essex for the last five years.

I had a job as a grounds man. I loved it and I kept working at it even though I was in a lot of pain with my arthritis. It meant being outdoors all year round and eventually my arthritis got so bad that I had to leave the job.

I nearly lost all my benefits. I was put in touch with an organisation to support me back in to work, but they don't support you if you can't read and write. Even the lady in my local pharmacy asked me what type of arthritis I've got. I have no idea. I didn't know there were different types. I didn't find that helpful at all.

Mencap have helped me though. I couldn't manage without them. They have helped me with a lot of problems. If it wasn't for them, I would've lost my benefits.

People want stuff to do. Imagine if it wasn't for Mencap, how many people would be on their own and lonely? I now swim and do drama. Once a week I play what's called healthy football for life. I was put on this course for 8 weeks, two years ago, but we've all just kept going. We play every week because the people in our teams wouldn't be able to play in regular teams. We enjoy it and it keeps us active. I also find that it helps me manage my stress and frustration. I also play hockey and visit a friend who has had his leg amputated so I keep him company when his wife goes out to the bingo on a Friday night. We met on a previous course about getting back to work and have stayed friends. I know the bus routes for all the places I need to get to: my step mum's, my friend's and for hockey.

I volunteer, but I would like to work. My clubs help me meet friends and Mencap is a real lifeline for me.



## BRIAN

### Brian is 83 years old and has COPD.

I worked in the city all my life and I was a heavy smoker until my mid 50s. I retired when I was 60 and was so looking forward to retirement, but in truth, it was a shock to the system. This was compounded by a bad back injury. It turned out to be a fairly bleak 18 months and start to retirement. I'm not sure I would have emerged out the other side were it not for my wife.

When I was 62, I noticed I was having breathing problems and was initially diagnosed with smoking related asthma and got an inhaler. The deterioration in my breathing has been slow, but in the last 7 years I've had to start taking steroids and there's now weeks in the winter where I can't go out very much. The winter can be hard and my breathing is so bad that I feel quite ill. When I was diagnosed with COPD, the doctor didn't tell me this disease is progressive.

Since I retired I've done a lot of education classes. GCSEs and A-Levels, but because I'm quite housebound in the winter now, I've not been able to continue with those things and it was through study that I met most of my retirement friends. Because I can't go out as much, my social circle is shrinking and if it wasn't for my wife, I would have quite lonely times. When we visit our children and grandchildren, my wife drives. I suspect I only have a couple of years of driving left.

I read books and I am interested in politics and current affairs. I like to walk to the shop in the morning to pick up a copy of The Guardian, but on the days when I'm not up to it, my wife goes. You see, I've got a problem with one of my knees which gives me a lot of pain, so the combination of that and my COPD means on a good day I can walk as far as the papershop, but I can't manage it every day. I've never been skinny, but clearly, because I'm not able to be so active, I've put on a few stone in the last few years, which of course, doesn't help my knee either. Food is one of the few pleasures I can still enjoy and if I'm honest, I probably take a bit of comfort in that. Family of course, is increasingly important. I'm a lifelong Spurs supporter and speaking to my grandchildren about football is one of my great pleasures. I use my iPad to keep up with Spurs news.

I've done pulmonary rehab a couple of times. Other than the fact that we share the same disease, I didn't have anything in common with the others. The first time I went I was probably one of the more healthier people there. I'm not on oxygen yet, but I am aware of the deterioration in my disease. I know my condition and my ability to be independent is only headed in one direction. I am fearful of what lies ahead, both physically and in terms of being quite cut off.



## COMMONALITIES

### Health

There is a reasonable evidence base for the causes of loneliness – poor health is overwhelmingly the most important factor. People in poor health are three times more likely to be lonely than people living alone for example. Most of the people we spoke to above were either experiencing poor health themselves or were caring for someone with poor health. Short periods of loneliness can be a good thing and can help build people's emotional resilience and self-esteem if they can tackle it. But there are also those who might need short term help or for whom being lonely is part of a more complex range of issues and who may need on-going support.

### Trigger events

Life events, or 'milestones' were often a trigger for experiencing loneliness: diagnosis, bereavement, loss of job for example. Some of these milestone events were planned – such as retirement – yet the reality of the actual situation can be very different from what people sometimes spend years planning for. Additionally, even planned for events can have a different dynamic, when accompanied with another unexpected change in circumstances.

### Helping others

Those who have experienced significant loneliness were keen to anticipate and support other people in their communities who might be at risk. There was a sense of an appetite to be connected to find these people; with the right framework and resources, communities are best placed to deliver support to those who need it.

### Talking

Just the sheer act of talking about loneliness seemed to begin to address its threat. That by discussing it, the truth of it and its ubiquity seemed to begin to change the shape of it and minimize its impact. And, of course, speaking to someone about your loneliness connects and re-engages you.