



Dementia Friendly Communities Insight Report

This report builds upon the Dementia Co-production Project Insight Report written by SILK in 2012 (<http://socialinnovation.typepad.com/files/dementia-insight-report.pdf>). This report features insights gathered during SILK's work on the Dementia Friendly Communities programme. We have found that many of the issues people living with dementia highlighted to us back in 2012 are still relevant; support, communication and diagnosis are still areas of concern. Discussions were based around the question "What does a dementia friendly community mean to you?" All quotes are from people across Kent living with dementia, caring for someone with dementia or from professionals during cross sector meetings.

KEY MESSAGES

Support for carers

Some carers we spoke to felt that they had received good support, *"I've been very lucky, as the help given to me by Jannette Olley at Carers First has enabled me to cope with my mother's dementia. The information given to me by her has enabled me to access respite care, arrange carers and thereby allow my mother (and myself) to have better quality of life."*

Some carers said that they didn't expect to receive any additional support, *"everything is stopping me living as I would wish but I have to accept that this is my problem and don't expect to offload it."*

Many carers and families said there was a *"fear for the carer of how they are going to cope as the condition worsens."*

Those who had been through this already discussed the toll it had taken on them, *"My husband died last year after some years of slowly losing his mind. The last year in a care home was very wearing and nearly killed me as well"*.

A big concern was where there is support it is not always joined up and this affects carer's ability to cope, *"No one is responsible for giving the carer help other than their area of responsibility. It is a nightmare and carers become desperate and ill themselves."*

Communications

People felt that at the moment communication is not joined up, this means it becomes hard to find the correct information at the time they need it or they find themselves having to explain their story or problems multiple times to different people and organisations.

"Holistic approach - once you contact one organisation, this should make all organisations available".

"We provide an advocacy service for people who suffer from Dementia in West Kent. Our experience tells us that if agencies and providers of care, health and housing etc had a more joined up and holistic approach to the needs of the person with Dementia, outcomes would be far better. The amount of stress and anxiety associated with having to repeat assessments, meet different people and fit different criteria is vast."

Day Care

There has been a lot of discussion about ensuring the person with dementia continues to have access to activities and a life outside of dementia and the home.

“Getting them out of the house helps otherwise depression sets in and a lot of sleeping in arm chairs!”

Although there are difficulties in trying to find appropriate places to go, *“It is difficult finding places to take those not yet 70 but who have behaviour which can seem antisocial in the general world.”*

Some people felt that they would benefit from *“better day care facilities, i.e. some activities that involve mental stimulation.”* *“Some day centres just seem to have games and singing as activities but more stimulation is necessary to keep brains active for as long as possible.”*

There was also an inconsistency in the quality of carers provided to families,

“I get fed up tidying and cleaning up after some of my mother's carers. Some of them show no common sense and always opt for the easiest way out. Others are absolutely fantastic and real gems, who ought to be encouraged to be loyal to the agency by offering them “bonuses”.

Diagnosis and Care Pathway

Some people are still finding it difficult when initially seeking help, *“difficulty in getting GPs to refer for Memory Testing and also on insisting on seeing the person with suspected dementia alone, with no opportunity being offered for the Carer/family member to also have their views and perspective heard.”*

Support and information once diagnosed was a big issue, *“people with Vascular Dementia being discharged from secondary care back to care of GP swiftly after diagnosis, probably due to no medication being prescribed. Carers sometimes feel they have been left without support, they often report that they are not given information about other sources of support that could be helpful at this point e.g. voluntary sector help via Carer and Dementia orgs.”*

People felt they would be more reassured if they had a better understanding of what was happening and what was to come,

“In the early stages after the initial shock of hearing the diagnosis, someone to come around and talk to you about what may lay ahead and what to prepare for.”

“Need a better understanding pathway of care available.”

“GPs/ District Nurses - how they can link all the services and charities and point you in the right direction?”

“Clear concise information of what is available to patients and carers of what help they can expect and how this care will need to increase as the illness worsens.”

Awareness/ Customer service

People highlighted how a lack of awareness of dementia affected their ability to carry out day-to-day tasks, in particular dealing with organisations by phone was problematic,

“Better understanding and training of those manning repair and out of hour’s phones for elderly vulnerable peoples’ needs. They require empathic approach and help.”

“Train people who work with the general public to deal with people who have dementia.”

As many services and daily tasks are now carried out online this poses a problem for those living with dementia (and older people in general),

“We need acknowledgement that elderly folk not always able to adapt to internet for appointments/information and patience required when dealing with someone used to the old ways.”

As a society we are moving away from face-to-face customer service and for people who need that kind of customer service it creates unnecessary worry.

“I went to a petrol station that was advertised as 24 hours. I filled up and then realised there was no one to pay and I had to use the self-service payment. I couldn’t do it and became very angry, luckily my wife was with me and she was able to pay for me”.

People shared good customer service when they had received it,

“I go into my bank and say I’ve got vascular dementia and sometimes forget to take my card or money when using the cash point. Someone from the bank stands a distance behind me while I use the machine and they remind me to take my card at the end.”

Cash point machines were often mentioned as a concern for people living with dementia,

“They now have adverts that pop up while you’re trying to enter your pin or get your money out. That can completely throw me. I’m trying to make sure I remember my pin and then an advert comes on and completely distracts me.”

Often a lot of worry is caused by people rushing around, quickly trying to move on to the next thing or next customer. It makes the person living with dementia feel very pressurised and anxious.

Travel

Travel and transport was often mentioned as a barrier for people living with dementia. A lack of transport is a problem or if there are transport options they can be too expensive,

“Transport issues particularly in the more rural areas, people cannot always access available services because they cannot get to them.”

“Kinds of travel arrangements for travel options for a blind man wishing to see his spouse in a dementia care home about 20 miles away and taxi quote was £50 one way.”

Where transport is available it can become a stressful experience,

“Not knowing where you are and what bus stop you have to get off at. The railway is better than buses as they announce where you are.”

“It would be good if we could have bus conductors back. The bus driver is too busy, he’s a one man show trying to do everything and doesn’t always have time to help”.

“Could buses announce stops like they do on trains and tubes?”

Personal safety

A lot of carers and people living with dementia said that worries about personal safety prevent them from living the life they would want.

“Personal physical safety is a major concern for families of those living with dementia. Without locking people up or monitoring them 24/7 there are several difficult issues”.

“For those living alone there are concerns over cooking/storing food safely or remembering to eat and drink”.

“A volunteer has expressed concern about a client’s lack of road sense, walking into traffic when outside with her.”

“Better maintenance of pavements, kerbs within Tunbridge Wells (and other areas), some areas are very hazardous”.

NEXT STEPS

The quotes collected here have informed the development of the Kent Dementia Friendly Communities programme. Each district in Kent has its own programme of activity and a variety of projects are being set up to address some of the issues raised in this report. A Dementia Friendly Kent web platform is being created to share information of the work taking place and the process each area has been through.