



## **Dementia Pathway Co-production Project**

### **Insight gathering with professionals, groups and people living with dementia**

#### **Initial Findings - February 2012**

##### **Introduction**

SILK were asked to work on this project as part of the Kent and Medway Dementia Collaborative's vision *"that people with dementia receive timely diagnosis and support that promotes their independence and helps them 'live well' with dementia, and that all services and support are provided to the highest possible standards: promoting dignity, choice and respect."*

In order to achieve this we have been using our project methodology which draws on the principles of co-production. By working with members of the public, people living with dementia and their carers alongside professionals from health and social care, community, voluntary and private organisations we aim to gain an understanding of the dementia care pathway from a different perspective and work alongside people to develop the project collaboratively. The insights gathered will inform commissioning and help to develop sustainable service solutions alongside the community.

The co-production themes we have explored are:

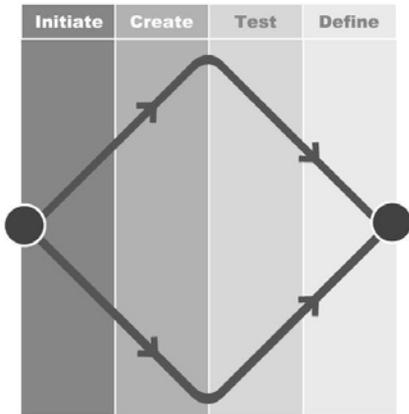
- Raising public and professional awareness and understanding of dementia, in order to reduce the stigma associated with dementia and encourage more people to seek diagnosis and/or support.
- Ensuring people with suspected dementia are identified appropriately and helped to make informed choices about their support needs, including whether or not to seek a formal diagnosis.
- Ensuring people with dementia (and their carers) feel supported and are able to remain as independent for as long as possible.
- Ensuring people with dementia (and their carers) are supported through periods of change.

We have worked with people across Kent aligning to the localities within social care:

- Dartford, Gravesham and Swanley
- Maidstone and Malling
- Ashford and Shepway
- Canterbury and Swale
- Thanet and Dover
- South West Kent (Tunbridge Wells, Tonbridge & Sevenoaks)

## **Approach/Methodology**

During this project we have been following the SILK Methodology, a tried and tested participatory project methodology which breaks projects down into four phases: Initiate, Create, Test and Define.



This report discusses what we have found during the Initiate and Create phases, Test and Define will take place in the next half of the project.

We had been asked to look at four broad themes around the dementia care pathway which were identified during an exercise held with the Dementia Collaborative Board on 9 September 2011, the themes were:

- Diagnosis**
- Information**
- Personalisation / Community**
- Services and Support Networks**

Initially we undertook desk research and carried out a literature review to understand methods used previously and to adapt our own methodology and tools as appropriate when speaking with people living with dementia and their carers. We learned that there had been very little work carried out previously which involved people living with dementia throughout the whole project but were able to gain an understanding of what may be achievable during this work. The desk research gave us an insight into the ethics we needed to take into consideration and helped to inform our own ethics statement. A 'topic guide' was developed as an aid to ensure that the different conversations held by SILK could be collated and compared easily once the initial insight gathering phase was finished.

Starting in September we began the insight gathering phase by speaking to professionals and frontline workers. These conversations helped us to understand the issues faced by those working with people living with dementia and their carers, and were also vital to identifying the different groups and people we would speak to.

Conversations with Day Centre groups, Carer and Peer Support groups were facilitated through the trusted frontline worker and were held in the usual group settings where people felt most at ease. Other group discussions were also facilitated by the trusted group leader to introduce the SILK team to the group. A few one-to-one conversations were held at the request of the individual and these were arranged at a time and venue preferred by the individual. A providers workshop

was facilitated by SILK with participants invited via members of the Dementia Collaborative Board. Please see Appendix 1 for a full list of people and groups spoken to.

Conversations were based on the four themes (information, diagnosis, personalisation and community support, and services and support). Even though the topic guide was used to help facilitate the discussion we allowed the group to lead the conversation and choose the topics they wanted to talk about so they could express their priorities and explain the significant experiences in their journey.

The purpose of the Create phase of the SILK methodology is to collect as many insights and ideas as possible. By speaking to professionals, people living with dementia and carers we have been able to build a picture of people's journeys and experiences across Kent. In the next section we will discuss the key messages that were brought to our attention as significant issues during the five month insight gathering phase.

### **Key Messages**

All quotes in the section below are from people living with dementia or their carers unless stated otherwise.

#### **DIAGNOSIS**

##### **Everybody is different**

While speaking to people about the care pathway one point was strongly emphasised – everybody is different. Every person that we spoke to also agreed that each diagnosis experience is different.

*“One person's diagnosis journey is never the same experience – we are all different”.*

The difference in experiences has been attributed to varying factors, including the character of the GP, the carer or the person living with dementia. Whilst acknowledging that this is not a problem in itself, it is clear that any particular service or support needs to be flexible enough in its approach in order to fit the different needs of people, rather than “one size fits all”.

Too often the diagnosis becomes the aim, when it should really be the start of the journey. It is a crucial point at which more support and direction needs to be given to people, you either stay on the radar or you are lost and picked up at crisis.

*“Within a primary care setting you see diabetes, asthma, heart clinics etc, but no dementia, it's like the poor relation that's hidden away from everyone else. It might make it more socially accepted”* (Professional).

##### **A more consistent approach to diagnosis is needed across Kent**

After speaking with many people across Kent about their experiences when they first approach their GP, it has become apparent that these journeys are very varied and inconsistent. People want a clearer and more consistent approach so that they can know what to expect during their journey.

*“Why can’t they tell you what’s going to happen at the start... Do they not know?”*

*“I went to the doctor with a memory problem, it took two or three more goes to make him understand. That’s only because that’s who I am, but some people can’t stand up for themselves and can’t be forceful to make the doctor understand”.*

### **People feel alone and left to find out and fight for themselves**

Many group members and their carers felt that despite so many people being involved at this stage of their journey, one professional after another, they still felt that they were on their own having to find out about either their specific diagnosis or what was available to them.

*“I had to organise everything for myself, I feel completely alone. The Care Manager is unhelpful, when she comes round she just confirms there is nothing that she can do.”*

It is during this time that some people can get left behind and fall off the radar,

*“It’s very much a case of ‘you shout you get’. Quieter people are often forgotten about”*  
(Professional).

### **Driving**

One of the main concerns upon receiving a diagnosis was whether people were able to continue driving. There was a lack of consistency between what different people had been told and this has led to confusion and worry,

*“I have been driving without a licence for a few months. I called DVLA who say they are very busy so I should carry on driving and ‘it will be ok’.”*

The worry of whether they will be able to continue driving, particularly for men, and the feeling that they will be losing their independence, along with the lack of clarity about where people stand may have wider implications than just the issue of driving itself.

*“Driving and the prospect of not being able to drive puts people off getting a diagnosis”*  
(Professional).

### **What happens after the Memory Clinic?**

While experiences of the memory clinic were generally good, there was confusion about who was eligible for the support courses available from the clinic. The main issue was when discharged from the clinic’s care people didn’t know where to go next or who to turn to for help,  
*“After the memory clinic, it’s like stepping off a cliff”.*

Even when people had been given the option of attending the courses beyond the care of the clinic there was still uncertainty about what next,

*“Our surgery was running a course, Dad went to a cognitive course for 10 weeks, Mum and I went to Carers Support for 6 weeks. Now that has ended and I don’t want Mum left in limbo.”*

*“You were told you had this disease and then told to basically get on with it... people have described the walk to the car as the longest and loneliest.”* (Professional)

## INFORMATION

### Information – both too much and not enough

People expressed that they had received too much information but at the same time not enough. People need the right amount at the right time in order for the information to be useful to them. They had received too much at the beginning of their journey,

*“I have a stack full of leaflets and booklets from many organisations given to us, it’s too much for me to go through to find one particular thing”.*

But then when they needed to find information quickly this was not always easily available to them,

*“When you call for help, you call for help NOW.... you don’t want to, or realise you have to, wait”* (Professional).

*“Quite often nothing gets done until someone is in crisis, by that point information is not useful to them”* (Professional)

Many people we spoke to felt that the information would be better if it was drip fed during appropriate times in their journey rather than everything at once or nothing at all.

### Face to face is best

While people appreciated the different ways of accessing information (e.g. online, by phone) the one way people wanted more of was face to face, someone to talk to. The people who were already attending groups appreciated the fact that they are able to get this,

*“Groups like this are worth more than any leaflet”*

*“If it wasn’t for attending this group we would not have known anything more”*

But acknowledged that not everyone is able or wants to attend these kinds of groups,

*“I wonder how people with dementia who don’t have a group like this cope.”*

As part of the offering of information available people want leaflets and the ability to look things up on the internet, but in some instances a little more is needed. For those who don’t have access to a group or an Admiral Nurse or Crossroads (which were also highly valued by those who had access to them) the option of having somewhere to go where you can speak to someone was one of the most requested things people we spoke to asked for.

*“The information needs to come from a ‘person’, once you have that initial contact to explain leaflets etc it works a lot better”* (Professional).

### The role of GP surgeries

People felt that GP surgeries could play a bigger part in the way that information is accessed. Whether as a place where information is kept or as a place where people can go for that face to face contact, there was a lot of discussion about the role local surgeries can play.

*“We regularly send brochures to GPs, they never appear in any surgeries though”* (Professional)

People see their GP surgeries as their first point of call and have requested that more work could be carried out looking into how surgeries could become better equipped to signpost people to what's available locally.

## **PERSONALISATION AND COMMUNITY SUPPORT**

### **Lack of understanding**

Out of all the groups and individuals we had spoken to not a single person was aware that they received personal budgets or direct payments. Even though at one group in particular the professional who ran the group was aware that everyone who attended was receiving personal budgets none of the people knew. It was felt that personalised budgets are too complicated and there was a lack of understanding from all sides about what they are.

*“Personalisation is a nightmare. Care managers don't understand Direct Payments so how should anyone else be expected to? It needs to be much simpler” (Professional).*

### **The appetite for community support**

People who had access to local support felt strongly that it was a lifeline to them,

*“This café gives you the chance to get out, talk and support each other, it's what is really needed”*

*“This café is our lifeline; it's an outlet for us.”*

*“The good thing about this group is that even though we're all different we can still understand each other – you can't get this anywhere else out there.”*

We came across instances where people had formed their own support networks, either through not knowing what else was out there or because the type of support they wanted wasn't available to them locally. There had also been examples of individuals attempting to reach out to others,

*“After I got my diagnosis I told my GP that if he sends anyone else to a Memory Clinic could he please give them my number. As I can understand what they are going through and they might want to talk to me.”*

People have demonstrated that there is a need for local, community based support and that there is a willingness from people to get involved in helping to provide this kind of support.

## **SERVICES AND SUPPORT**

### **Support for carers**

In some cases carers felt isolated and that all support and services were aimed at the person with dementia. Carers are not involved or supported throughout the process and not given practical support in doing everyday tasks, i.e. shaving.

*“No one thinks about the carers and the fact that there is so much change for them”.*

*“Who do you turn to when you need help?”*

However, carers that attend group sessions are highly supported and valued, a few people have to travel long distances to attend and this is sometimes down to long waiting lists in their immediate areas.

*“Groups for carers (at Age Concern) are fantastic – I wish it could be every week”*

### **Support courses from the Memory Clinics**

Six week support courses are offered to people once diagnosed and are based within the memory clinics. Many people spoke about these courses – if you were able to get on one they were worthwhile – however, if there was not enough people booked up, these would not run and it could take weeks in some instances for them to be fully booked in order to run. Support after these courses was also varied amongst people living with dementia.

*“Nothing after diagnosis and the 6 week course”.*

### **Self-funders**

During the providers workshop it was felt that self-funders, after their initial assessment from social services, are left on their own to sort out the support they may need.

*“Self funders are the losers – doors close” (professional)*

Some self-funders may be able to push and be successful in arranging support, but some may not. Some will struggle on their own until they reach a crisis point when they will be picked up again by social services.

### **Small and Locally Run Support Groups**

In some areas of Kent there are small and locally run support groups. These were set up by volunteers and run on very little or no budget at all. These groups are highly valued by the people that attend them and demand for more like these is high. However, the volunteers that run these are concerned that any small amount of funding they might have received is likely to run out in these difficult times. An idea is perhaps for these smaller groups to come together to bid for funding rather than all compete against one another. Commissioners could identify gaps in provision and these groups could respond together.

*“I struggled to get my husband to a group – but now he’s here he loves it”*

*“You need to be a special type of volunteer to be able to give out the correct information – it is not a matter of training” (Professional).*

### **Providers Workshop**

A workshop was held with providers who run services across Kent. Some of the opportunities identified during this workshop included:

- Giving carers the opportunity to continue to care for the person living with dementia, should the person be admitted to hospital. This ensures care is consistent and from someone who is trusted and recognised already. Also to look at the support needs of people who come out of hospital but may still need extra support in re-adjusting once back at home.
- Smaller providers could work together in order to submit bids and move to specialist markets.
- Create a change in the perception of the care industry by working with schools to raise awareness among young people that caring is a career option, rather than a last resort.

Once we had held these initial conversations with the various groups and professionals we collated these insights into POINTS (problems, opportunities, insights, needs, themes, system challenges). This way we were able to theme any ideas that were emerging and highlight what the main opportunities, problems or needs were.

Before presenting initial findings back to the Dementia Collaborative Board in December, we checked back with the various groups and professionals the main points based on what they had told us. Groups agreed that what was being presented back was indeed a true picture from their point of view and some members have offered to meet with the Board to discuss these further.

### **Opportunities and Next Steps**

From the many conversations that were carried out, a number of ideas have emerged:

#### **Information**

- Review how DementiaWeb and 24 hr phone line are promoted and create promotional materials alongside people, aim to raise awareness and reduce stigma
- DementiaWeb and 24hr phone line should work hand in hand to be the single point of contact – they need to be consistent with each other i.e. same information available from both places
- Review and user test DementiaWeb to ensure it is user friendly and easy to navigate
- Information for younger people about dementia, e.g. book or DVD. We will work alongside younger people to design some information working in conjunction with Faces of Kent (formerly Swale Carers)
- Create a 'checklist' of dementia symptoms. The list can be used by people who are concerned and taken to the GP while expressing their concerns of the symptoms they have. The checklist can link to the helpline that can support people who are trying to get a diagnosis.

#### **Support**

- A range of people providing 'drop ins' where people can speak to someone face-to-face. Locally based e.g. community centre, library, town centre, cafe
- Mentor/buddy/peer support – once diagnosed people are offered a 'buddy' who can be their contact when they have questions or a 'friend'. Different types of buddies for different situations. For example a buddy could be someone living with dementia, an Admiral Nurse, Professional and non-professional buddies
- Volunteers – unlock the potential of volunteers and the role they can play within the pathway
- Circles of support – working with people to create 'circles of support'
- Shared Care – looking into ways carers can support each other. Look at possible models of how care can be shared

#### **Pathway**

- People would like a better understanding of the pathway they can expect. So that everyone can expect the same or if not at least understand why their experience is different e.g. courses after diagnosis
- Create a standard offer of support that people can expect to receive in each locality
- Exploring with GPs what would make it simpler for them to diagnose or refer. Link to ADSS work already being tested with GP surgeries
- People would like to be able to get information about local support from their GP surgery
- Can memory tests be carried out in alternative settings? e.g. Day centre

The next step will be to take these ideas back to the people and groups we have spoken to and gain an understanding from them on which ones they would like to take forward. Once we have the ideas and the people who want to work on trying to achieve them we will invite professionals and members of the Dementia Collaborative Board to work alongside us in trying to create or address the ideas that have been suggested to us during this insight gathering phase.

The ideas and suggestions that people have given us align with some of the recommendations from the Dementia Select Committee report. In particular:

**Recommendation 5**

To ensure young people have a good understanding of dementia.

**Recommendation 11**

That KCC ensures that people living with dementia and their carers have access to good quality, well maintained information on local services and support in Kent and in their local area.

**Recommendation 12**

That KCC and Health Commissioners should ensure that every Kent district or borough has at least one memory cafe as well as peer support for people with dementia. That KCC should promote the grass roots development of a network of memory cafes and peer support by engaging local groups.

## **Appendix 1**

### **People, groups and organisations spoken to (September 2011-January 2012)**

People living with dementia and carers:

- Keith Oliver (one-to-one conversation)
- Maidstone Carers Support Group
- Maidstone Peer Support Group
- Maidstone Dementia Café
- Shadowed four people living with dementia
- Canterbury Age Concern Carers Support Group
- Informal 'tea afternoon' held at someone's house, mix of carers and ex-carers
- Whitstable Dementia Café
- Tudeley Day Centre
- Ashford Peer Support Group
- Lunch Club, Tunbridge Wells
- Northfleet Day Centre
- Estuary View Surgery Patients User Group
- Hawkinge Day Centre

Professionals:

- Kate Sergeant, Alzheimer's Society
- Jacqui Wharrad, Admiral Nurses
- Victoria Hare, Estuary View Surgery
- Tina Stirling, Alzheimer's Society
- Ellie Potier, Alzheimer's Society
- Jo Jones, Alzheimer's Society
- Penny Hibberd, Dementia Services Development Centre
- Anthony Smart, Alzheimer's Society
- Manager, Collins Unit Canterbury
- East Kent Independent Dementia Society
- Irene Jeffrey, Crossroads
- Sue Wrintmore, Westgate Integrated Care Centre
- Rock Sturt, Alzheimer's and Dementia Support Services
- Viniti Seabrooke, Alzheimer's and Dementia Support Services
- Community worker, Crossroads
- Providers workshop (attended by: Ann Taylor, Kevin Parker, Britt Gulsnaker, Mary Beckett, Kevin Post, Ann Davidson, Richard Macintyre)
- Goodman Centre, Age Concern
- Claire Bateman, FACES of Kent (formally Swale Carers)
- Sue Scanlan, Dementia Advocacy
- Bridget Withell, EllenorLions Hospices
- Elizabeth Pilgrim, Dementia Information Service Co-ordinator