

The Dementia Diaries: a resource for young people

Emma Barrett and **Laura Embery** describe how a process of creative co-production in Kent led to the development of a powerful resource on dementia for young people, which is now being distributed internationally

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*You can buy *The Dementia Diaries* online for £5.99 via Amazon.*

The Social Innovation Lab Kent (SILK) is a small team based within Kent County Council that was set up in partnership with a company called Engine Service Design in 2007 to use design-thinking to 'do policy differently'. SILK's early projects led to the development of a human-centred methodology and toolkit which draws on tools from social science, community development, business and design. By working in a participatory way across sectors and disciplines, the SILK approach is able to address seemingly intractable and complex problems. It can be applied to strategy, service design and sustainable community projects.

Critically, every SILK project starts with people. SILK recognises that everyone – whether in a personal or professional capacity – can contribute and that the best understanding of a situation comes from people who are closest to the issues. SILK facilitates a diverse team, including people with direct experience, through a collaborative, iterative process to genuinely understand a given situation and identify opportunities for improvement, and in so doing generate collective ownership of design, delivery and outcomes.

In this article we explain how the SILK approach shaped the development of a resource to introduce dementia to young people – a book called *The Dementia Diaries* – in 2013.

Phase 1: Initiate

In 2011, a Kent County Council Select Committee on Dementia conducted a wide-ranging review on the state of dementia care in Kent, and one of a series of recommendations was that Kent County Council would fund a youth project to raise awareness about dementia and produce some sort of resource on dementia for young people (KCC 2011).

Shortly after this, SILK was commissioned internally by Strategic Commissioning in Adult Social Care to undertake a project to look at a wide range of people's experiences of the dementia care pathway. Much of the initial insight gathering for



The editorial group in action at a meeting with Matthew Snyman

this project – from people living with dementia and professionals across Kent – reaffirmed that working with young people should be a priority in order to tackle stigma. One of four ideas to arise out of this initial project was 'a book for children and young people'.

From the outset, as in all projects, we included people whose insight, knowledge and perspective would add value to both the process and outcomes. A Kent charity, Faces of Kent, which supports young people currently caring for relatives, initially put us in touch with young people.

Phase 2: Create

At our first gathering, we brought together a group of about 20 young carers between the ages of 7 and 17 to discuss and review existing films and books about dementia aimed at children and young people with. After initial discussions we were left with a core group of young people and staff to discuss the look, feel, format, requirements and specification.

This core group suggested a book in the style of a journal, inspired by the *Diary of a Wimpy Kid* or *Adrian Mole*. Participants decided they needed to create something for young people "who didn't really know what dementia was", that "did not seem technical and scary" but will give young people an "understanding of dementia and what happens when someone has it". They wanted the journal to be "fiction", but that the "stories should be based on real life", so that the "facts are accurate and feelings are real".

At the next meeting the core group created a storyboard (a rough graphic setting out what each page of the resource might contain) which included written contributions from young people with relatives living with dementia. This started to bring the initial concept to life – *The Dementia Diaries* was born! Together the group drafted a letter to invite other young people with experiences of living with a family member with dementia to take part in the project and share their stories. The SILK team was then able to distribute this letter via their existing networks across Kent.

Starting in early January 2013, Emma (co-author here) spent time having conversations with eight families from across Kent in their homes about their experiences of living with dementia. The discussion was primarily with the grandchildren of people living with dementia, although parents, and sometimes other family members, including pet dogs, also took part! There were no specific questions, rather areas of discussion about feelings and relationships, memorable stories and specific events, shared interests and how they changed over time, reactions from the wider community and key messages for others. It was an emotional and humbling experience. Although the plan was to spend an hour with each family, often we were still deep in conversation several hours later!

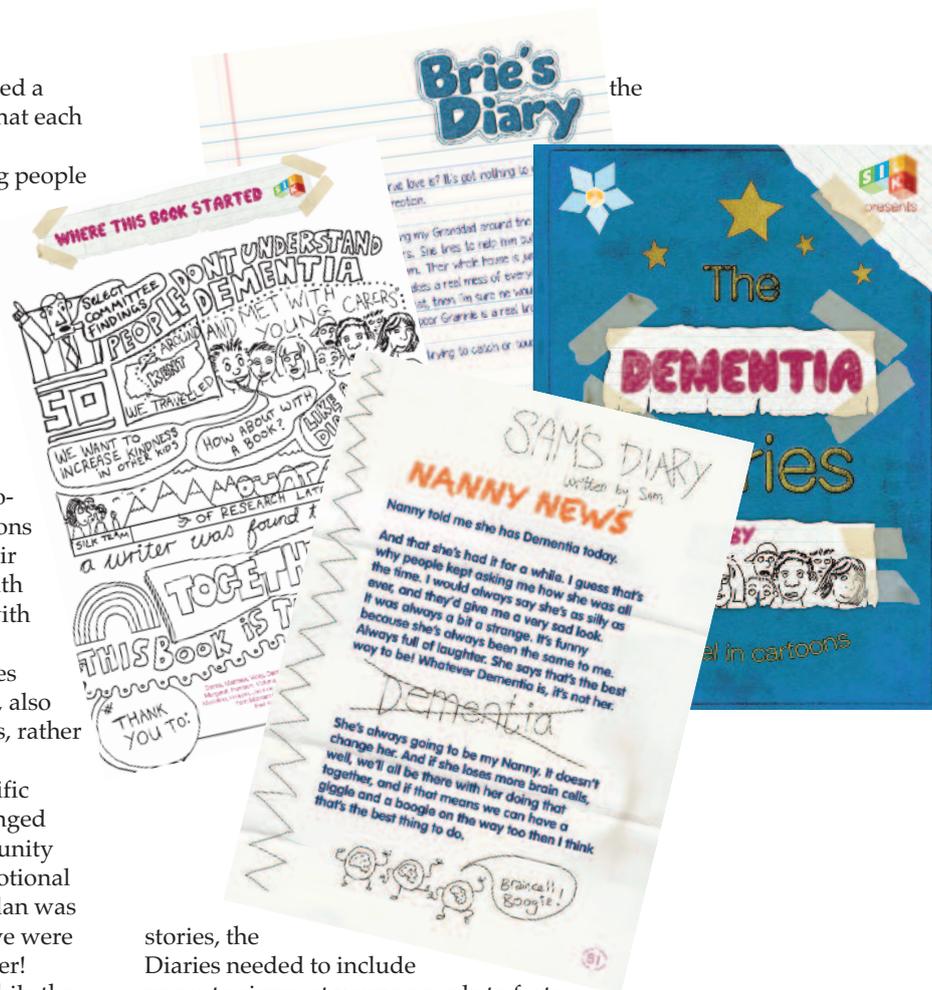
The interviews were then transcribed while the SILK team set about looking for the right person to turn the interview data into a book. Matthew Snyman, an internationally recognised animator and film-maker, who grew up in Maidstone, fitted the bill perfectly. Matthew read through the huge amounts of material and began to condense and share the stories among four freshly created characters: Brie, Fred, Sam and Sarah.

Phase 3: Test

The first time Matthew came to meet the group was in February at New House Youth & Community Centre in Sittingbourne. This was the first ‘public reading’ of the initial story drafts with lots of excitement that it was now becoming real. There was also time to reflect on the significance of sharing stories to support others in similar situations.

All the participating families were now invited to attend meetings and/or had regular email updates about the project, depending on their location. Participating grandchildren came from across Kent: from Westgate-on-Sea, the Isle of Sheppey, Snodland, Maidstone, Newnham, Cranbrook and further afield from Swansea in Wales. This group became the editorial group for the project and were involved in reading through drafts and commenting on style, format and content, and later in the making of two short films, both related to the Diaries. The group included some of the parents and grandparents and a wider circle of experts including a community librarian and Admiral Nurses from Dementia UK.

A couple of significant changes came from these meetings. Firstly, it was decided that in addition to



stories, the Diaries needed to include pages to signpost young people to facts and information about dementia. SILK approached the Student President from Mid-Kent College who was able to facilitate students from the social care course to research and design this section of the book. Secondly, although initially all participants were deliberately kept anonymous, as the project progressed they appeared to get strength in numbers and were happy to identify themselves in press interviews and photos as contributors and part of the editorial group.

Phase 4: Refine

Roll on a couple of months and the book was ready. Good fortune enabled us to share a final draft with Angela Rippon, the TV presenter and co-chair of the Dementia-Friendly Communities Champion Group (part of the Prime Minister’s Dementia Challenge). After reading it through she provided a wonderful foreword:

The Dementia Diaries is a delight and a revelation. The thoughts of these young people coming to terms with the effect that dementia has on much-loved members of their families are humorous, humbling and overlaid with uncompromising honesty. They demonstrate a remarkably mature and uncomplicated approach to the condition and their grandparents. I think it’s brilliant to see Brie, Sam, Fred and Sarah representing a dementia-aware generation who will mature into a society in which dementia is understood, dementia patients are respected and the word ‘stigma’ will no longer be part of the Dementia Dictionary. These aren’t just diaries – they’re a real beacon of hope for the future.

I work in a Home Treatment Service supporting those with a diagnosis or probable diagnosis of dementia. *The Dementia Diaries* is a wonderful book, appropriate for all ages. I was pleasantly surprised at how light-hearted some entries were, how they made me smile. This publication could well help reduce the stigma attached to a diagnosis of dementia. I’m sure it will positively affect families, children, and carers that others have similar experiences and there are positive times rather than just the daunting ones portrayed on television.

Jennifer Cooper, mental health nurse, Kent

The Braincell Boogie

Well I know you love to dance and hell I love dancing too
yeah but the braincell boogie is not a dance you choose to do
Yeah, allow me to explain exactly what I mean to you
Someday a friend or family member might forget your name
Wear their socks over their shoes or have a tendency to go astray
But it's important to remember that as people they are just the same
cause I'm talkin' 'bout dementia and it starts a boogie in your brain
It's scary and overwhelming so be patient try to be humane
Go with the flow, let them do their own thing

It's just the braincell boogie, the braincell boogie
yeah just the braincell boogie, yeah the braincell boogie
braincell boogie we're boogieing the night away

So when they're wearing three shirts, three jumpers and a cardigan,
When they're fighting with a scarecrow and everybody's watching them,
Don't ya try to intervene, just sit back and enjoy the mayhem yeah
It's just a journey that they go on, so make sure you're going along too.
Try to lose your inhibitions let them do what they gotta do
Extra visits are important, bring your friends and family too.

Yeah! It's just the braincell boogie, braincell boogie
yeah just the braincell boogie, the braincell boogie
braincell boogie, why you boogieing in my brain?

► After a few enquiries we decided to set up SILK Publishing, which enabled us to retain ownership over data and ensure a quick turnaround – the first print run happened in May 2013. The first round of distribution was to all the participating grandchildren and families who all received 10 copies each to share within their own networks and this was followed by distribution to every school and library in Kent.

The Braincell Boogie

Throughout the project we had aimed to reach as wide an audience as possible. Initially the hardcopy version had been the priority so that it was appealing to all generations; however, discussion in the group soon led to realising that it was important to have something available online to raise awareness about the resource, and dementia more generally, aimed at young people.

The result was 'The Braincell Boogie', a catchy jingle about dementia which we uploaded to YouTube (the lyrics are in box above and view it on www.youtube.com/watch?v=93gGPdrnMG8). The idea had come from the group talking about the success of the Australian public health advertisement that became a huge hit thanks to the internet: 'Dumb Ways to Die'. The group watched it together, and then Matt drew up some ideas for an animation and words for 'The Braincell Boogie'. He brought these ideas back to the group – and the process followed a similar journey to the Diaries, until we had a finished product.

The launch

The premier of 'The Braincell Boogie', which now has over 6500 hits on YouTube, and launch of *The Dementia Diaries* took place on 27 September 2013 at County Hall in Maidstone. A diverse audience was in attendance, with the youngest aged two

and the eldest in his 80s, reflecting the range of support for the project. We were really pleased that Hilda Hayo, the UK's Chief Admiral Nurse, was able to attend alongside the Dementia Matron and nurses from East Kent Hospitals University NHS Foundation Trust, social care strategic commissioners and Kent County Council cabinet members. Most importantly, all the grandchildren were able to attend along with grandparents, family and friends. All were welcomed with pizza, cake (in the image of the Diaries) and popcorn to celebrate the huge achievement.

Next steps

As with all SILK projects, it is as important to record and share the process, as much as the finished product. In this project we worked with the editorial group to create an eight-minute film, called 'Making The Dementia Diaries' (which can also be viewed on YouTube at www.youtube.com/watch?v=sYYVSRWCAA).

After covering all Kent schools and libraries, our distribution strategy has been demand-led. We were really pleased to be approached by Surrey County Council Dementia Friendly Communities Team to purchase 1000 copies for their schools and libraries.

We are currently developing a loan scheme and a sale or return offer for charities. It is also available to purchase on Amazon for £5.99 with all proceeds ring-fenced to go back into developing a dementia friendly Kent. Furthermore we welcome anyone wishing to exchange a testimonial for a free copy.

The next exciting development of this work is to take the Diaries online and develop an interactive learning resource. We are currently working with schools, colleges and community groups across Kent to test out how the resource is being used in practice and are using this evidence to inform the design and development of a teaching resource which we anticipate will be available later in 2014 – a resource to develop the workforce of the future.

The final word

As the saying goes, 'mighty oaks from little acorns grow'. What started as a small idea has grown organically: from writing a blog about the project for the Department of Health's website, to a publicity tour in Demark, to being highly commended in the NHS England Excellence in Participation awards (the Children and Young People's Award). From nurses in Sittingbourne to the Bahamas, they all recognise that the stories in the Diaries are not about labelling people with an illness, rather they are about relationships between families and friends. Feedback is telling us what started as a book for young people is now being used by all ages.

Why has it been successful? The SILK approach does not aim to segment or categorise, rather it aims to take a whole systems approach to change, which is how we all view the world in our day-to-day lives. The SILK approach starts with people and demonstrates how stories, connections and relationships can change lives. We hope people will listen to the stories in *The Dementia Diaries*. ■

Reference

Kent County Council (2011) *Dementia: a new stage in life*. Select Committee Report. Maidstone: KCC.