

Connected Compassionate Communities

Connected Compassionate Communities (CCC) is a three-stage programme commissioned by Birmingham and Solihull Combined Commissioning Group (CCG) Frailty Board. The aim of CCC was two-fold: -

- 1) To develop a care pathway for frail older people living in the communities of Birmingham and Solihull that includes them and their families and carers in the process.
- 2) To explore ways in which to connect potential stakeholders in order to create a more cohesive community wide approach in the support of the elderly population.

Particular emphasis is placed on those people living with dementia, their carers and family members, as well as those who provide services from health and social care and third sector organisations. The CCG represented health and social care statutory providers and local authority partners as well as some members from third sector organisations.

A desired outcome of CCC would be: - The development of a co-created, more robust care pathway and dementia strategy that supports people to live in their homes as participating members of the community and to receive appropriate health and social care support from both statutory and third sector organisations as and when they are required.

While previous work had identified the basis of a pathway, it was felt by the CCG that more extensive consultation and involvement between health and social care providers and those living with dementia could benefit and better inform its further development. It had also been acknowledged that focus of the work to date had been on the latter stages of the pathway and there should be a shift to earlier parts in 'the journey' of older people. The frailty board had identified that this shift would enable older people in the community and in particular those living with Dementia to have a better and more enriched quality of life with more timely and appropriate support. Essential to this would be the voices of those living with Dementia, their carers and family members as well as those third sector and community organisations who have regular contact with people living with Dementia and frail older people living in the community.

The focus of the first phase of CCC was on the communities that straddle the Stratford Road. Stratford Road runs from the centre of Birmingham itself in the north through to Solihull in the south. The demographic make-up of the communities change significantly as you travel along Stratford Road from north to south. The north portion contains a very densely populated cosmopolitan range of BME communities, predominately South and North Asian communities together with a good mixture of Irish, Jewish, Chinese, Somali, Yemeni and Afro-Caribbean communities. While some of these communities remain evident as you travel towards Solihull, they become more diluted as the level of white working and middle classes increases. Compared to the top (Northern) end of Stratford Road, Solihull is visibly more affluent. The CCG was keen that BME communities in particular were included in the project as they had significant levels of under-diagnosis for Dementia and related illnesses. It was also felt that levels of support from the health and social care sectors for the BME communities was more fragmented. The BME communities in the northern part of Stratford Road were also identified by the CCG as 'hard to reach communities'.

The Connected Compassionate Communities programme was based on the eventual development of Action learning sets (ALS) that would include participants from the whole health and cultural economy in Birmingham and Solihull. Action learning sets (ALS) would be set up to help identify how provision is currently organised. Through the process of shared learning each ALS would use the information gathered through narrative collection and their own experiences to try out new ideas in response to people living with Dementia, carers and family members in order to improve quality of life and wellbeing. It was also crucial to ensure

that third sector organisations, community groups, cultural leaders and artists were also part of the ALS. The view was to help connect each to each other with a focus on supporting older members of the community through localised community based activities.

There were three stages to the programme. **Stage One** involved scoping and making contact with what already existed within the community for those living with Dementia, carers and family members. A database was established containing over 400 organisations offering everything from day care to arts and crafts.

Stage Two involved collecting individual and group narratives. This was done by engaging with and alongside individuals - people living with Dementia, carers and family members, community groups, statutory providers and third sector organisation. We encouraged others to identify the issues and benefits of existing provision and to record their experience of 'being in the system' as a user of services. These narratives were recorded on video where consent was given and in note form if preferred. The data was analysed for themes. Recurring themes were identified and became the basis of a 'report back' to those who took part. Participants were invited to an event held at Bristol City Football Club on the 11th October 2012 where the outputs from the research were presented for validation. It was important to ensure that as many voices as possible were present and 230 delegates were able to attend. Video and notes were presented to delegates containing the emergent themes gathered through stage two. Themes were clustered in the pattern of previous pathway work done by the CCG: -

- Dementia Awareness and Symptoms.
- Recognition and Assessment.
- Living with Dementia.
- Acute/Secondary, Residential and End of Life care.

Once checked for validity, six initial action-learning sets were set up for further work during the day. Outputs from these groups would further inform the research and identified how people around the table could contribute to improving the quality of experience of those living with Dementia, carers and family members.

These outputs were presented again to statutory providers via the CCG. This was then used to inform the development of a Dementia Strategy for Solihull and Birmingham.

Stage Three will involve the formation of two pioneering Action Learning sets. It will take place over an 18-month period. This will enable new ideas and ways of working to be tested and evaluated by health and social care practitioners, third sector organisations and community groups. Each ALS will meet to share learning gained from trying new approaches that have been recommended and identified through stage two of the programme. Each ALS will also include service user involvement in an inclusional and responsive way in the future development, design and delivery of Dementia services that are locality based and community driven to help support the frail elderly in the community itself. The starting date for stage three has not yet been agreed.

Without a doubt the level of 'take up' in this programme is significant. The time spent developing relationships, having conversations in order to develop mutual trust in order to address the desire for improvement was an important part of the process. This was particularly the case in BME communities. These communities were previously subjected to a whole series of myths as to how they supported their elderly population, particularly those living with dementia. Diagnosis and recognition within the BME community was further compounded by members of the BME community stating there was a cultural stigma '**we hide it, we hide the facts**'.

The most frequent recurring themes identified by CCC were: -

Stigma: cultural, personal, institutional, social, clinical stigmas that fed fear and disablement and in some cases total isolation from both statutory and third sector support.

Disconnection between services within health and social care across the whole health economy exacerbated this experience based on an experience and understanding of a downward spiral in such a progressive chronic pathology. This would often present itself as, *'people keep asking us questions or doing survey about what we want – but nothing changes'*.

Lack of 'real care' that was person centred with little or no recognition of the individual was a common experience.

Accessing entitlements to support, means tested or otherwise was always a big issue with many from the BME community feeling 'let down' by a system that created insurmountable hurdles and culturally inappropriate services.

Participants were also able to identify a list of non-clinical or social care interventions that they believed would help to enrich the lives of their frail older people that current commissioning arrangements overlooked. Consequently better more informed commissioning was sought to help particularly those BME communities to help themselves.

The development of locality-based partnerships was seen as desirable, however funding arrangements and commissioning worked against this. Instead it was identified that groups were encouraged to compete for funding from a dwindling pot.

By working together and sharing experience and learning, CCC has enabled levels of involvement and in particular from the BME communities that has been historically unprecedented. The focus on building trust through fluid communication and relationship building has enabled many individuals to disclose some very pertinent issues. This programme is about learning together to bring about transformational change by connecting communities of people together in the development of a community of practice based on the need to develop an inclusional and responsive frail elderly pathway. It is not about creating "add on" training of staff or "bolt on" of new protocols. It is important for the flourishing of these communities in the future that we enable the narratives of people living with dementia, their carers and family members to tell a story of improvement. We can help to achieve this by ensuring that provision within communities is really locality based and reflects the social and cultural makeup of the communities it serves.

A Summary of the narrative evidence collected can be viewed on:-
<https://vimeo.com/63396880>

Videos used on the 11 October 2012 can be viewed using the following links:-

- 1 CCC - Introduction narrative of people living with Dementia their carers and family members - issues and perceptions <https://vimeo.com/61190089>
- 2 CCC - Recognition, Assessment and Diagnosis - narrative from people living with dementia their carers and family members <https://vimeo.com/61050579>
- 3 CCC - Living with Dementia - narrative from people living with Dementia their carers and family members . <https://vimeo.com/61029795>
- 4 CCC - Residential, secondary end of life care - narrative from people living with Dementia their carers and family members. <https://vimeo.com/61705797>

- 5 CCC - End piece - celebration of Life affirming energy from people living with Dementia their carers and family members
© Naidoo and Associates 2013

<https://vimeo.com/58200081>