Creating a comic about living with dementia

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'<u>Comics creation with people with dementia</u>', a project funded by Arts Council England, has been piloting a collaborative, patient-led approach to health comics creation. A group of nine people living with dementia, supported by dementia advocates from the <u>Beth Johnson</u> <u>Foundation</u> in Stoke-on-Trent, have worked alongside artists <u>Cathy Leamy</u> and <u>Jessica Lucas</u> in a series of arts workshops to find ways to represent and depict their experiences of the condition in a comic format.

There are many <u>existing comics</u> and other narratives about dementia, but the majority are written from the perspective of carers, family members, and others who do not have the condition themselves. This can create a gap in understanding around what it is like to have dementia and how those with dementia would prefer to be treated. In this project, we therefore directly engaged people with dementia in the design of a comic, ensuring their perspectives remained at the centre of the creative outputs.

To produce the comic, we held a series of five workshops over the course of a year, which I facilitated. Workshop activities included discussing the impact of living with dementia on participants' daily lives; deciding on the key messages for the comic; providing feedback on character design and constructing biographies; and plotting potential storylines, as well as commenting on a series of progressively more developed drafts of the comic.

We used various activities to identify key messages to convey in the comic, including group discussions about dementia stereotypes versus reality, and asking pairs of participants to complete speech bubbles for characters with dementia. The messages they shared included: "See me, not my dementia"; "I have dementia, but I'm still able to live well" and "It takes a little longer, but we get there". Participants stressed that, while a story needs to be realistic, it should also show that it is possible to live well with dementia.

Another message the group emphasised was the importance of a support network, including peers, family, professionals and community members – to reinforce the message that living well with dementia is not something that can be achieved alone. We therefore worked together to created a series of characters who would interact with and support the people with dementia in the comic, including family members, but also people within the wider community, such as service sector staff.

The title of the resulting comic, <u>'There's No Bus Map for Dementia'</u>, was selected by participants. The idea that everyone progresses at different rates and there's no single 'map' for dementia arose when participants were asked to draw visual metaphors that represented dementia for them. It was striking that a number of participants drew routes, maps or forms of transport. The idea of 'dementia as a journey' is, of course, a common metaphor, but 'There's No Bus Map for Dementia' challenges the familiar notion of dementia as a 'downhill' journey by emphasising that, with support, the journey need not be a negative one.



Photograph of participants and a dementia advocate plotting initial story ideas and commenting on character designs

We were keen to ensure that the design of the comic was accessible to people with dementia, and also to readers of a range of ages and abilities. We therefore opted for a simple four-panel layout that the group felt was easy to follow. Based on participants' preferences, we opted for full colour and clear, simple images. The amount of text is limited to ensure reading the comic does not require long periods of concentration. Furthermore, all the text is in the form of dialogue, making the story easy to read aloud and share. In addition, the comic is divided into short one or two page mini-stories that can be read individually.



Example of a page from 'There's No Bus Map for Dementia'

As well as the comic, we produced a <u>guide to comics creation</u> based on our experiences in this project to help other groups living with dementia (or with other health conditions) to carry out similar projects of their own.

Involvement in the creative process certainly had positive outcomes for participants. As a dementia advocate commented, "Members are delighted with the outcome noting how all their comments, ideas and thoughts are in the comic. The activity has certainly helped to support members in their mission to show you can live well with dementia and be a productive member of society. Producing the comic has given members who are already proactive a desire to be involved with more initiatives relating to dementia."

Print copies of the comic are <u>available to order</u>.

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