

**A new picture book explores the landscape of dementia**

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# A new picture book explores the landscape of dementia

Positive examples of how to live well with dementia can be hard to find, but **John Killick** and **Claire Craig** have found a creative solution in the form of a picture book which they believe will counter the negative images

**B**oth of us have long memories of living through times when dementia has consistently had a bad press. We still regularly see descriptions of it as “a disease”, claims by organisations about their attempts to “fight it” and to fund and find “a cure”, and references by carers to dementia as “terrible”, “horrible”, “the most feared illness” and “destructive of identity”. The results of all this negative publicity are that anyone newly diagnosed is likely to feel they have been given a death sentence.

Instead, we firmly believe that dementia is “a condition” with multiple causes, that the social and psychological aspects are just as significant as the medical, and that the balance constantly needs to be redressed. We take every opportunity to present positive examples of how it is possible to live well with dementia.

## Presenting the positive

The idea of a special booklet as a contribution to this process came out of a conversation between one of us – John Killick – and Sally Graley, a dementia officer from Kirklees in West Yorkshire, who has since been involved with the project throughout. Sally came up with the title of the booklet too: *Discovering Dementia*.

John took the plan to the other co-author of this article,

■ John Killick is a writer and poet, and Dr Claire Craig is professor of design and creative practice in health, Lab 4 Living, Sheffield Hallam University

Claire Craig. The timing was perfect. Claire had just secured research funding exploring the role of design and the arts in challenging dominant medical discourses around ageing. Her enthusiasm and the funding turned a concept into a reality.

First of all, John drafted the outline: consisting of a series of double page spreads, each asking and answering a series of questions which the illustrations would reflect. Claire found a young London artist, Sophie Standing, whose previous work seemed to reflect the approach, and she produced a first draft. It was then decided to pull away the scaffolding and let the pictures tell a less dogmatic story. Now the titles for each pair of pages are suggestions only, and the quotations from people with dementia at the bottom of the second pages are similarly complementary.

The metaphor of a journey through dementia is a cliché but Sophie has developed it in a number of ways, only actually portraying it at the beginning and end of the book. The graphics are the key element of *Discovering Dementia*; they are not photographs but imaginative recreations of an idea.

## Possibilities explored

There are no facts involved, rather, possibilities explored which the viewer is free to interpret in their own way. We would like to suggest that one approach could be for discussion of each illustration with another person or in a group. In this way the book can be best seen as a work of

art, open to interpretation and judgement.

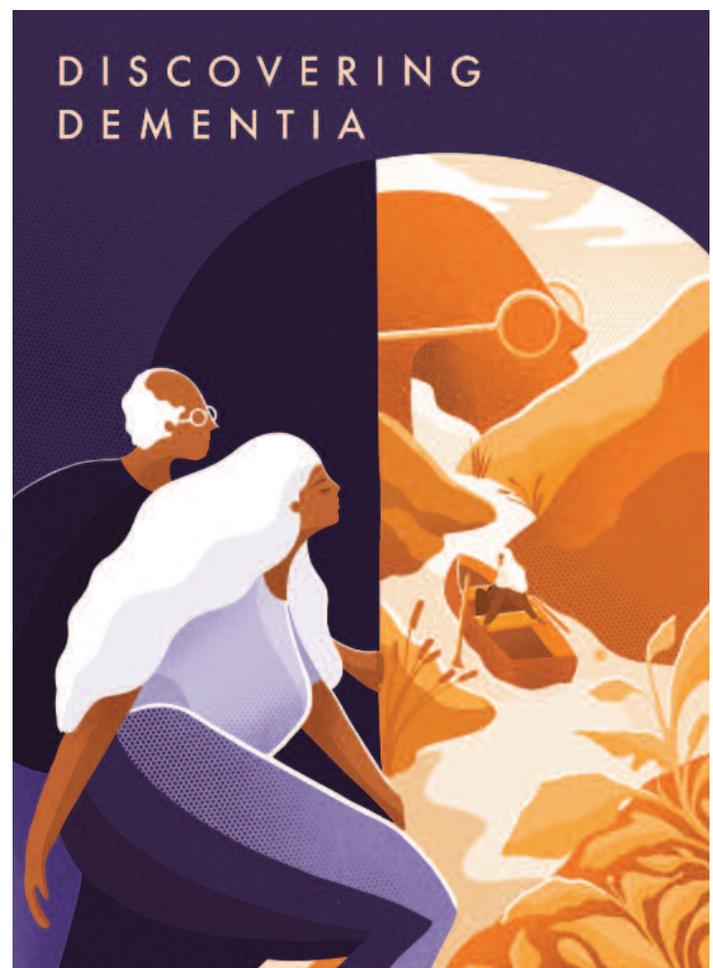
There is another aspect of the graphics to which we wish to draw attention, and that is the colour schemes. The artist has deliberately designed the left-hand pages to reflect darker moods than those of the right so there are a series of progressions towards the positive. The reader may well absorb this message unconsciously.

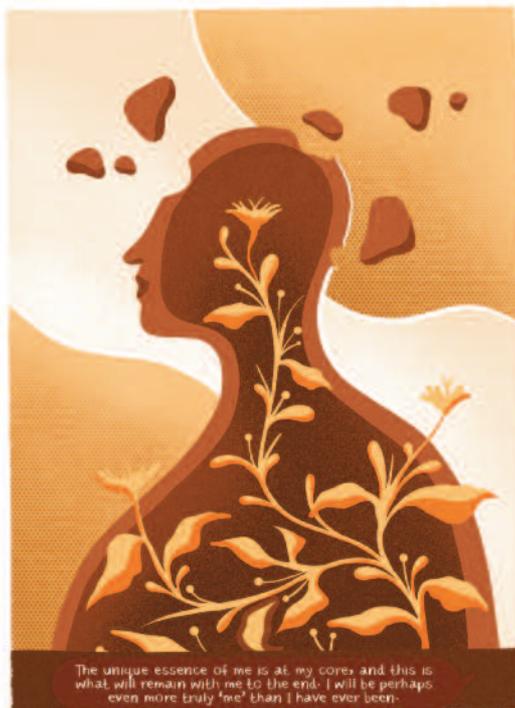
The front cover of the book (below) shows two individuals

who are met within its pages and the image of a boat by which the landscape is to be explored. And one of the double page spreads, to take an example from within the book (pictured, top right) reflects the kind of emotions someone with the condition is likely to experience.

## Growth and wholeness

This particular spread has the title “Selfhood” at the top of the left-hand page, while the picture under it is in purple





**Left: Two double page spreads from *Discovering Dementia*: 'Selfhood' and 'Interests'. Artist: Sophie Standing**

focus is to collect more thoughts and responses to the work.

To date, we have sent copies of *Discovering Dementia* to over 100 people including people with dementia, family members, clinicians, artists, designers and academics. Individuals have commented that they have seen nothing like this before, suggesting that it is like something more akin to visual poetry. One occupational therapist described it as:

*A beautiful thing to be giving to people at a point of their lives where everything is upside down. At diagnosis they are given all these facts. To have this as part of their package would bring some comfort to people.*

A volunteer co-ordinator from a care home said the book felt “like silk”, imbuing a “sense of peacefulness and calm” which was, above all, “thought-provoking and wonderfully positive.”

The arts play an important role in how dementia is portrayed and understood. Certain media representations serve to reinforce negative stereotypes which can undermine selfhood. Our hope is that this book will challenge existing genres of publication, providing an alternative picture of hope and potential

Our intention is to make *Discovering Dementia* available throughout Britain in doctors’ surgeries and hospitals. We want this to be free of charge and to this end we are actively seeking a sponsor.

To find out more please contact Claire Craig: [c.craig@shu.ac.uk](mailto:c.craig@shu.ac.uk)

*Discovering Dementia* is published by Sheffield Hallam University and was launched on 17 February 2021.

and black suggesting gloom and presents the figure of a person who is in pieces. The suggestion is that awareness of the self has been disrupted.

On the right-hand page the picture, which is in brown and yellow suggesting a lightening of the burden, the individual stands tall, with a human-size plant complete with buds and blossoms growing up through the body. This hopefully carries the message of growth and wholeness.

The quotation at the bottom of the page comes from the Australian Christine Bryden and reads, “the unique essence of me is at my core, and this is what will remain with me to the end. I will be perhaps even more truly ‘me’ than I have ever been”. The picture of perceived partial disintegration is mirrored on other pages, such as those depicting “Confusion” and “Language”, and that of foliage occurs on the “Help”,

“Relationship” and “Interests” (pictured above) pages as well as on both the front and the back covers.

### Helpful feedback

People living with dementia gave feedback to early double page spreads as they emerged and offered really helpful insights in relation to how they saw the pictures, shaping some of the detail such as the size of the font. Now that the booklet is finished our next