Live Well with dementia programme:

the design, development and value of a programme based on self-management principles for people living with early stage dementia
Background …

Research in 2013* found that people with dementia have much less access to the benefits of Self-management programmes, compared to other long term conditions.

* University of Brighton : Literature review
The design …

Aim: to help people living with early stage dementia develop the understanding, skills and practical tools, to empower and support them to take an active role in the management of their health and well-being.

The **voice** of the lived experience of participants and **their response** to the programme in development is directly informing the model.
The journey of development …

5 pilot programmes in 2013 - significant adaptation in 2014

19 pathfinder programmes in 2015/16 - further adaptation in 2015

20 programmes planned in 2016 – with focus on positioning the programme within a timely offer of post diagnosis support

Project completion March 2017

The internal and *external evaluation of each delivery phase has informed the guiding principles of the programme in development.

* Commissioned from the University of Brighton 2013 - 2017
The development … examples

Informed choice and control: Pre programme meeting for participants

Person centred approach: a flexible not scripted programme structure

Responsive and responsible: real time feedback
  : content about ‘what is dementia’
  : involvement of ‘chosen supporters’

Peer support: participants are a resource for themselves when together as a group. The dynamic of people sharing and learning from the experience of others is a significantly valued aspect of the programme. This has become more explicitly developed in the framework of the programme approach.

alzheimers.org.uk
The latest design ... seven co-facilitated sessions

* Life after diagnosis - what Living Well with dementia means to me
* Living Well – managing dementia in my daily life
* Keeping the balance – managing My Health
* Keeping the balance – managing My Feelings
* My Support – Communication and Relationships
* Myself, My Support, My Future planning
* Market Place of information, support and signposting - this session will involve supporters by participant invitation.

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"I attended the Living Well with Dementia Course at the Alzheimer’s office in Shipley, West Yorkshire in September 2015. It was a 7-week course.

The course helped me to realise that I’m not alone and dementia does not stop me doing lots of things I enjoy. I may need to ask for help along the way, but no shame in this. Dementia is the same as any other illness."
What have people said?...

It is clear that this programme remains at the cutting edge and at the forefront of a very current and developing area of research and interest. University of Brighton researcher 2015

This is a journey of development from a generic self-management starting point, to a programme fully informed and influenced by people with the lived experience of dementia. Project team member 2016

It is a privilege to have opportunity to work more directly, more closely and more alongside people living with dementia, than ever before. Live Well with dementia programme facilitator 2015
The Value ...

I have found the motivation to do more things

It’s like taking some control of your life again

Delighted and surprised, I didn’t expect it to be so positive

It’s been the learning together and from each other that’s the best part for me

It’s a privilege to be with others - I now feel proud and I am not ashamed to say I have dementia

This has really helped me, really glad I came

I feel much stronger now than I did before
Thank you

Kevin Scanlan
Living with dementia

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Kevin’s wife

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