‘A Good Life With Dementia’
Shared learning amongst equals

Damian Murphy
Innovations in Dementia, UK
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Damian

Innovations in Dementia CIC

http://www.myid.org.uk/

A little about us

Innovations in Dementia

- **Justice** – Rights drive our work
- **Warmth** – Acknowledging daily human encounters
- **Open** - To growth, potential and WONDER
- **Brave** – Inspiring Different Conversations

What we do

www.myid.org.uk

- Rights
- Accessibility
- Dementia Voices
- Belonging
- Recovery and Discovery

The birth of ‘A Good Life’

The very first question I ever asked – and still have to ask.

‘Why does everything seem to be directed at the person WITHOUT the diagnosis?

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So, you think you're clever

'My Dementia'

My A$%*e!

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The birth of ‘A Good Life’

Bring your ‘loved one’

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‘It’s nearly as good as toast’

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A post diagnostic course for people living with dementia

People with dementia as course designers

People with dementia as course tutors

Inspiring Different Conversations

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https://www.youtube.com/watch?v=XRS4Aha068Y

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Aims of the Course creators

- We want to go from sad faces to happy faces
- **We don't want people to feel afraid any more**
- We want people to be more aware of their abilities and potential – 'I CAN live with this'

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A Good Life With Dementia – the course

How was it for you?

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D.

I've met so many nice people to help you with your thinking

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I had been feeling so lonely but am so pleased to have come

This is a really positive atmosphere

Everything I've heard - I've felt 'that's me' and I thought it was just me.

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J.

It's super lovely. You can feel it in people's voices. You feel loved.

You feel that someone has got their arms around you.

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M.

As the most recently diagnosed it is so wonderful to see and realise there is so much less to worry about now

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Insights – What is dementia?

C. It's other people saying 'don't be silly' and 'why did you do that?'

W. 'your brain is not connecting'

M. 'I can't think before I speak'

W, 'It's like the Tin Man in Wizard of Oz, 'If I only had a brain'!

P. 'it's waiting for the next word to trip me up whenever I'm speaking'

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Insights – What is dementia?

T.

My head started to feel really empty… I felt I was always in contention with someone else but didn’t know who they were.’

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What dementia means to me

BOB

To know I'm still me and to ask for love and a gentle reminder in case I've forgotten to put my trousers on!

So what is it about A Good Life?

"I was sceptical about the Course.

As a former journalist I hoover up information, and had made a point of learning as much as possible about dementia.

So I wondered if it was worth my while attending.
It most assuredly was - as it enabled me to process the emotions around my life sentence.

And to find a new purpose in life." Participant in Fife

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Manifesto examples

Around the time of diagnosis

Services are providing the wrong things and are not listening to what we are saying we need!

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Our statements

- **Dementia is not our fault**

- **So what if we repeat things.**
- **So what if we repeat things.**
- **So what if we repeat things.**
- Respite is not about moving out it is about a healthy space for all

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A G L W D does not stand alone

It opens a dialogue – we now need to keep the conversation going

It creates new active engaged interested groups of peers.

It creates a virtuous cycle of learners becoming tutors.

It can form part of a whole new culture of learning and development led by people with dementia

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- We've facilitated dozens of Good Life programs across the UK
- Several new peer groups in the DEEP network
- The Good Life resource booklet
- Shaping the regional 5 year dementia plan
- Co-producing learning and development eg licensed taxi drivers, public health team. **'Real people in front of me'**

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What can we all do?

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- Take the lead from people with dementia
- Properly listen to and tap into the hitherto untapped resource of people with dementia and their supporters
- Involve people with dementia in the design and delivery of all dementia learning in your area and in research too!
- Let's not ADD this to our workload – let's revisit how we operate to enhance the contact we already have with people with dementia in our area.

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Finally – some food for thought

The ‘trickle down’ idea that if you provide good carer support, it will eventually benefit the person with a diagnosis of dementia, is a myth… (what about those people who live alone, too?)

It may sound counter-intuitive but if you want to address carer burden, then put something practical on for people with dementia.

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Thank you. Any questions?

Damian@myid.org.uk

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