The ‘People with Dementia CAN!’ Gathering:

BETTER TOGETHER!

Here we are!
You and me!
Share our ‘cans’
Set them free!

For everybody has some way
To bring the bright
To find a way

YOUR way to be
In happy thoughtful voice!
It’s up to you!
Then make your choice!

Be who you are!
Stand up and say
This love of life has come your way!

There’s nothing new to shout about!
This love of life
Will lead us out!

Bob Long
Beverley Racecourse, 18th June 2025

Introduction:

This opening poem was composed by Bob Long when present at the recent People with dementia CAN gathering where 50 people living with dementia came together to 'share our 'CANS' and set them free!

After giving a little background and context to the gathering, I will share an outline of the influence that peers living with dementia are already exerting across Humber and North Yorkshire.

As well as gathering to celebrate, we gathered to work too. I have therefore also collated the answers to two key questions we posed on the day:
What are your messages to other people also living with dementia? and
What are your messages to the wider world?

Finally, I will share reflections on the gathering, on the answers to those 2 questions and highlight key elements where people with dementia CAN fulfil and contribute to (and in many cases already are!) the 6 priorities of the Humber and North Yorkshire dementia strategy – 'Hope of a life still to be lived'.

A Little Background

For about the last 4 years or so Innovations in Dementia have been working with East Riding of Yorkshire Council on a commission entitled, 'Co-Produced dementia programmes'. Through peer-led and peer-created post diagnostic 'Good Life with Dementia' courses, new groups of engaged, interested individuals with dementia have emerged across East Riding. The idea of bringing them altogether at some point in a real face to face meeting did not take long to take shape.

This could just never have happened 4 years ago – well it could, in fact have happened. The people with dementia have always been there! The problem is that (as in most areas across the country) priority was not given to the importance of a space for people living with diagnosis of dementia to come together.
Today, it seems unthinkable that such a platform didn't previously exist.

Current impact and influence

What an achievement in 3 years; to make so many challenged people feel so positive….we feel blessed that we have been involved in your success in making the East Riding more dementia proactive and positive.

Gordon had a wonderful day and getting up to speak made him feel valued again. I could almost see his chest puff out, I know mine did

So, thank you and, if there is ever anything that we can do to support the cause, please ask. We'll always give it our best shot.

Val

The morning was spent with groups saying hello, sharing messages and achievements and the influence they have had in many different ways.

I loved that Gordon felt that way and was able to say what he said even though it wasn't easy for him. Alongside other members of the Beverley 'East Riders', the Market Weighton 'Saints' (nothing holy about them!) and the Bridlington Right Minds, he has taken part in a co-produced training session, 'Engaging in everyday situations…with people with dementia'. Gordon completely won over the local taxi drivers he spoke with.

The Local Public Health team and dozens of the '40+ Health-checkers' too shared how having real people in front of them for a couple of hours was worth so much more than days of online dementia programmes.

I loved that my co-presenter David made a joke about repeating things by repeating it… and then repeating it again!
I loved that it didn't matter and that John was able to say, 'We've got dementia, so what?!

I loved that likewise Robert could joke that, thanks to becoming a little more disinhibited, he could get up and share his story and tell more of his jokes. He was also at pains to say how much he cares about others, and about how he loves to help reassure his peers as a tutor on the Good Life course – despite being told with his fronto-temporal diagnosis that he'd have no feelings!

I loved that Kay came up for the East Riders. And did what she does at the meetings – be present, smile and enjoy the Liquorice Allsorts.
All sorts indeed! I love that our groups and those present were made up of people of every ability, despite the myth that it's just for the eloquent.

I loved that York Minds and Voices could share their beautiful quilted banner made by a local artist who captured the groups words over several months.

I loved that Phil shared how encouraged he felt to continue to set up his own peer group in Brigg – already named, 'Phil's Friends'

I loved how the As Time Goes dementia café group will now look to provide that important space for members with dementia too in Hornsea, as well as wanting to 'bagsy' the next Good life course!

I loved how the Right Minds group has become a vibrant, lively and influential movement across Bridlington – willing to go anywhere to hear the latest hits played through an electronic violin! (each to their own!)

I loved we heard the value and potential of people with dementia being involved as part of a dementia research advisory group, backed up too by the presence of groups (Minds and Voices) who've led on their own research as part of the national Dementia Enquirers project.

In short, the gathering itself, as Val explained in her message above, was a momentous day, and a tangible demonstration of the power of peer support and of the potential of people with dementia to contribute to, help shape and also lead on key aspects of dementia care services.

In fact, it's clear that a lot of what the strategy seeks is already happening. People with dementia are leading the way.

And that was just the morning…

Questions of the day:

1. **What are your messages to other people also living with dementia?**

There are **huge and consistent messages of encouragement** at hand. People with dementia are best placed to help peers get over and get used to the blow of receiving a diagnosis. This is what happens at the good life course. It can and does counteract those messages of a feeling of doom and gloom, of being left on a cliff edge; or being left without hope. It fits perfectly with the recovery model.

It's an individual journey, learn what works, stick to it and stay optimistic
Stay positive or it drags negative thoughts about your ability to live a good life.
Learn to be patient, accept it is a different way of living. You have to adjust.
Don't be demoralised
You can be yourself.
Keep on trucking
Don't stop doing things.
You can't go back so just look forward – and do what you CAN in the moment.
We can still make our own decisions
Don't be frightened to ask for help
Positivity leads to longevity!

The group also recognised the importance of **the message that life goes on**, that a diagnosis is not the end. More than anyone, it's people with dementia who can say to their peers that there is hope of a life to be lived, whilst being truly able to say 'I know how you feel'

Life is still worth living – there's always something you can do (maybe something different)
Don't let it stop you doing anything. Make the most of your life
Have as much fun as you can.

Live life to the full. There's still a life to be lived.
We didn't ask to get this – it is not our fault.
Don 't be afraid.
You're not on your own and it isn't the end and you will find this out as time passes.
It's not the end of the world. It's not a death sentence. Get on with your life.

This encouragement is backed up too by **practical advice around adjusting to the diagnosis**
Focus on what you CAN do not on what you can't
Best talk about it- you can't blank it out – embrace this new way of living!
Don't be scared to speak for fear of judgement
We recommend the Good Life course for everyone.
There's so much more help out there than there used to be.
Get on a course – join a group of peers. And get the Good Life booklet
Educate your local GP surgery and others
Make sure you get your attendance allowance!
Don't over analyse
Try not to doubt yourself – if YOU know it's right then it's OK
Trust your own judgement.
Don't panic. You can make lots of friends – the best years are to come, I know mine have.

And taking steps to **tap into peer support** – precious help at this time.
Talk and share with others also diagnosed. We haven't got all the answers
'Joining a group was the best thing I ever did'.
You get to meet lots of people. You are not alone.
In our Right Minds group we're all in the same boat - we look after each other.
You're not out to sea.
We DO matter – tell everyone!

2. What is your message to the world at large?

So, we saw the extent to which people with dementia can be a huge resource for each other. But it is people with dementia who can also guide and shape services, if services choose to (and they should!) take the lead from, to hear and heed the voices of people with dementia.

What people with dementia are asking/demanding. A lot of these also reveal that the problem and thus barriers to progress lie not with anybody's dementia but with other people!

Messages to ALL other people
Don't be embarrassed to talk to us
We can do things. Please don't think we can't
I've got dementia – so what? Dementia is not the end of the world. So don't write us off!
Our journey can be positive – help us don't hinder us
We're not stupid – we've only got dementia
We are still real people.
Never say, 'You don't look as though you have got dementia' – it only makes you look stupid!
There IS a life still to be lived with dementia
Don't treat me differently
We DO matter
Stop communicating the disease in a negative, depressing way. It turns everybody away.

Messages to people delivering services There's a clear recognition that, although people with dementia CAN, interdependence is preferred to complete independence and that it's ok to ask for help as below:
If there's something for care partners then there must be something parallel for people with dementia too
Help us get to what really helps out there – groups etc. It's not just about medication and reviewing that.

'My memoir needs a lot of aide'
Appreciate that it takes a lot of effort for us to get other people to understand. So be patient if we lose track rather than rubbing it in!
Put dementia under neurology instead of mental health service.
Help us take the first steps in setting up a group
Advertise the Good Life course at the time of diagnosis – at the memory clinic and the GP surgeries
Put some money into funding services.
Handholding please rather than signposting
If you're a supermarket, stop moving your stock around!

And that **interdependence by definition is a two-way thing so,**
Listen to us, understand our problems – you can better help us then. Instead of deciding what you think we need!
Listen to me. If I say something is wrong you have to listen to my real feelings.
Don't undermine us. Do not make horrible, depressing adverts on TV. Show some positive adverts about dementia
Help us break the stigma. Don't be embarrassed to talk or ask about dementia
Acknowledge how dementia makes us feel – eg our loneliness, guilt and often fear.

People with dementia cannot be ignored
We are not invisible – don't treat us so. We are still relevant!
Let US talk
We can still VOTE! And have rights!
You need to listen to people
Give us easier access to info – if on line tech leaves us behind then it's not progress – don't deny us access to simple written info.
More face-to-face contact please
We are not invisible – don't treat us as so
Don't exclude us from the party!

People with dementia are a huge mostly untapped resource
We can do things. Please don't think we can't
People with dementia have the experience and therefore more knowledge of living with it (in our heads!)
Listening to people with dementia gets results
We can train young people and staff and workers all over town
We have a lot to offer.

In summary the message is clear that there is a strong desire to be involved, included and heeded in all aspects of dementia care. It's time to move further away from 'doing to' and much nearer to 'doing with' people with dementia.

Humber and North Yorkshire
Health and Care Partnership
Innovations in Dementia
EAST RIDING
OF YORKSHIRE COUNCIL

People with Dementia CAN!

The Minds and Voices banner.

I'm me

We've all got minds
and we've all got voices

‘Hope of a life still to be lived’. Reflections on the Gathering and the Humber and North Yorkshire dementia strategy

So, what does this all mean for the new Humber and North Yorkshire strategy? We have reflected on the answers to the questions above and the conversations we have held with local people with dementia, mainly in the East Riding area, over the last few years. Below we lay out some ways in which people with dementia can play a key role in bringing the priorities of the strategy to life. The priorities are as below:

1. **Prevention**
2. **Innovation and Research**
3. **Accessibility**
4. **Communication**
5. **Education**
6. **Future-proofing**

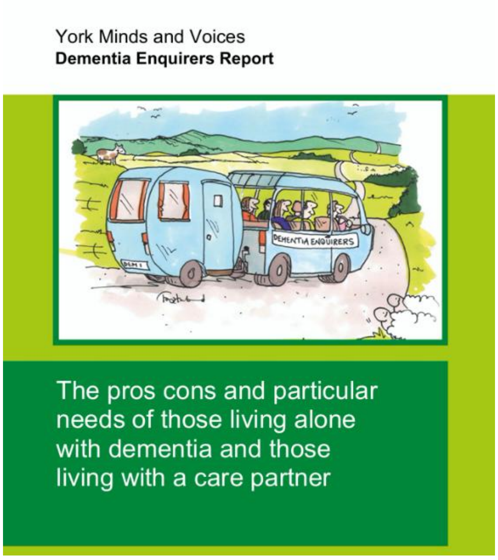
1. **Prevention –** People with dementia through coming together in peer support play a huge role in preventing things getting worse for each other. It’s a perfect forum to share and live out those encouraging messages laid out above.
   We have seen the belonging, camaraderie, warmth, welcome and emotional support go beyond preventing things getting worse. It transforms people’s lives. Time and again across the county we hear people with dementia saying I’ve never had such a busy social life.
   That encouragement and the very testimony of people as living proof of a life after diagnosis, can complement the work of the ‘brain health’ post holders across the region

2. **Innovation and research –** People with dementia can and do play a huge role in leading on research.

People are now coming together regularly across the area. When that happens, questions inevitably arise in conversation. Those questions are worth investigating. In fact, their very origin makes them valid and current.
At Innovations in Dementia we led the ‘Dementia Enquirers programme https://dementiaenquirers.org.uk/.

In preparation for the Gathering we asked people with dementia if they saw themselves as researchers**.** Many said no. But when people understand that it is about asking questions and following up on those questions, people soon realised they CAN see themselves as researchers.

Members of the Minds and Voices group were on hand to share that they had led on their own Dementia Enquirers’ research project.
The Gathering was a reminder that any dementia related research that does NOT include people with dementia as advisors or co-researchers (or both) just doesn’t receive funding these days.


York Minds and Voices
Dementia Enquirers Report

The pros cons and particular needs of those living alone with dementia and those living with a care partner

It was great to hear from Stanley on the day about his role as part of the Hull University Dementia research advisory group. How great that across the county we are building that resource of engaged interested people with dementia who can both fuel new ideas and scrutinise others.

3. **Accessibility –** This is very much about the clarity of published information.
   We've heard across the groups about the importance of face-to-face contact and of having human beings on the end of the phone rather than not automated messages with options.

   People with dementia have already played an important role in how the new strategy is formatted and laid out.
   Steve Milton, a fellow co-director of Innovations in Dementia worked alongside 100s of people with dementia to co-create the accessible writing guide http://www.innovationsindementia.org.uk/wp-content/uploads/2023/01/accessible-writing-guide.pdf **.** The Humber and North Yorks strategy document uses those principles.

   Simple walk-throughs, or more formal environmental audits carried out by people with dementia have already been used to great effect by:
   - the Right Minds group who contributed to the way-finding and improved accessibility at the Bempton cliffs nature reserve.
   - York Minds and voices at the venue in which they meet and their local general hospital and
   - East Riders at the Haltemprice leisure centre.

   This growing resource of people with dementia can be drawn upon for more regular such undertakings under the accessibility element of the strategy. What a resource!

   Clarity of language and information too so it is also linked with the next field of …

4. **Communication –** this is a two-way thing. Historically people with dementia have been told what is available, told to fit in with whatever is on offer.
   People have also NOT been told where they are in any process – such as the diagnostic process.
   For example, many memory services talk about diagnostic pathways.

   Right from the very first meeting to co-produce this new strategy, the late Dr Wendy Mitchell said that as we are all individual, we need our own 'crazy-paving' rather than having to fit on someone else's pathway.

   We heard at the Gathering, and previously across the peer groups in the region, how much of a resource people with dementia and their supporters are. 'Listen to me', 'Talk to us!'

   The establishment of a network of groups (like that emerging across East Riding) has already opened a dialogue and we can keep the conversation going. This creates a constantly up-to-date understanding of what people are asking, declaring and experiencing at any juncture.

   Thus, people with dementia can be a huge resource in setting the agenda for service reviews and improvement. As part of the Communication priority, we can broaden this platform of engaged interested voices of people with dementia across the region.

   Services by their very definition are to 'serve'. This new strategy, and the scaffolding we are creating of voices of people with dementia, now requires servant leadership from those in key positions, taking the lead from those seeking 'Hope of a life to be lived.'

5. **Education –**Historically, training and education is focussed purely on staff, yet this group is only one third of the broader cohort of learners – the others being people with dementia themselves and their supporters.
   People with dementia have learning needs (The Good Life course is an obvious example of meeting some of those needs); and care partners have learning needs too.

   Who better to learn from than people living with dementia themselves? That goes not only for working staff but also care partners, supporters and the public at large.

   Those present at the gathering called to be able to train youngsters, GPs, other professionals and the public at large. The clear messages to, and expectations of, the outside world can form much of such learning.

   We have already had examples of this through the co-delivered ‘Engaging in Everyday situations’ short courses delivered to public health staff, private hire taxi drivers and 40+ healthcheck teams across East Yorkshire.

   At the people with dementia CAN gathering, care partners were queuing up to declare how observing other people with dementia speak and meeting with care partners in the parallel space provided during the Good Life course have given huge benefits to them too.

   This itself raises another interesting question as to whether a lot more carer support can be provided through programmes designed by and for people with dementia!

6. **Future-proofing – It is so much more than design!** –What the Gathering clearly demonstrated is that future-proofing is also about creating a sustainable platform where dementia is met with a greater degree of equanimity by all at every step.

Ideally now, from around the time of diagnosis up to the time around end of life, there is hope balancing out the doom and gloom. ‘I’ve got dementia so what!’

The Good Life approach has been described as the bedrock of the recovery model – not recovery from dementia, but recovery from the hopelessness, the huge blow to confidence, and the fear and self-limiting ideas of withdrawal that so often accompany a diagnosis of dementia.

Consistent delivery of peer led learning opportunities and peer support across the Humber and North Yorkshire we can create a whole new generation of people living as positively as possible with dementia.
It would need communities that are much more understanding and collaborative playing their part in that interdependent relationship that those present at the Gathering called for.
Year on year we can continue to shift the narrative away from that of stress and burden that has prevailed since the founding of Alzheimer’s Society in 1979 as a carers’ organisation.

Humber and North Yorkshire Health and Care Partnership
Innovations in Dementia
EAST RIDING OF YORKSHIRE COUNCIL

People with Dementia CAN!

The Minds and Voices banner.

We are birds forever in flight

Stand up, stand out, rejoice!

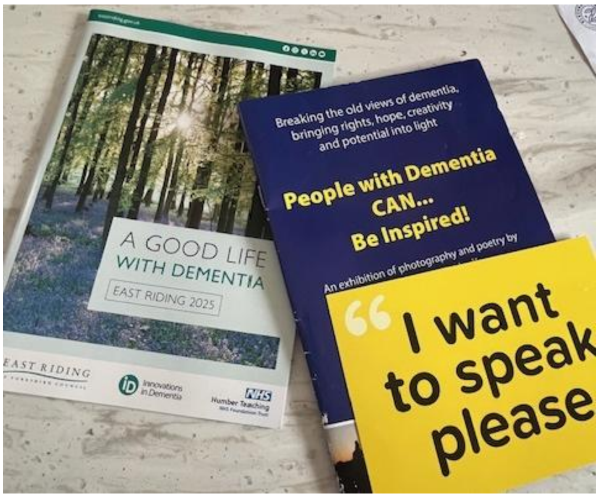
Summary

The ‘People with Dementia CAN!’ gathering at Beverley Racecourse opened with a reminder that there is a vast difference between living with dementia in your head and living with dementia in the house.

This day was very much celebrating the potential and achievements of people living with dementia in their head. It also served to highlight the very practical role that people with dementia can and are doing to make the Hope of a life still to be lived a reality across Humber and North Yorkshire.

We hope this can be the first of many and larger gatherings. In the meantime as we’ve said enough for now, back to Bob to sign us out.

There’s nothing new to shout about!
This love of life
Will lead us out!



Damian Murphy
Innovations in Dementia.
June 2025