

# Minds and Voices

Opening minds and moving forward

## OUR DEMENTIA STRATEGY FOR YORK

### Background

***‘What is good for people with dementia is good for everybody’***

From ‘Creating a dementia friendly York’ (Dean, Crampton and Eley for Joseph Rowntree Foundation 2012)

During November 2020 we met weekly to create a dementia strategy for York that was clear and easy to understand and to act upon (whether you are a person with dementia, a care partner, a service provider, shopkeeper or bus driver). We have drawn on our own experience of being diagnosed and living with dementia in the York area.

***‘It has to be clear and simple to understand’***

We agreed that our strategy should be split into four parts.

#### **1. Before diagnosis**

- Promoting awareness, challenging myths, a call for transparency

#### **2. At the time of diagnosis**

- Positive language and Hope through research

#### **3. Post diagnosis**

- Services to fit us rather than us having to fit services

#### **4. The future**

- Ongoing support that is not time-limited

In each part we will offer some thoughts, share our experience and will recommend real and practical solutions.

***'They just talk to my daughter now about me. It's as if I don't exist'***

***'We ALL have Something to offer'***

***'Do not treat us as if already dead'***

***'The recent news about Sir Bobby Charlton diagnosed with dementia – it was like an obituary'***

***'People with dementia aren't zombies – Apart from when I want to be!'***

***'Whenever some star gets dementia it's all over the press, but there's thousands of us and people should hear about all of us, about what we can do and what we are doing to make the best of it.'***

**Two real stories :**

**MARY**

***'I'm me, I'm me! I'm NOT an idiot!!'*** cried Mary recently.

She is afraid of acknowledging her dementia all because of the stigma of dementia. She thinks that dementia will make her an idiot. That's just not fair.

**RICHARD**

Richard was asked what his biggest complaint about living with dementia was.

***'Other people'***, he said immediately. ***'they test me, talk over me, blame me, speak to quickly for me, ignore me, treat me like a child'***

It's not the dementia that makes us suffer.

For the Richards and Marys we want to say, ***'IT'S NOT YOUR FAULT!'***

## Solutions

- **Take the lead and learn about dementia from OUR experience** There are 2,000 or more people with dementia across York. We are a big resource.
- **Challenge the stigma about dementia thus:**
  - Health care professionals to make it normal to talk about dementia freely and openly and realise there is a life still to be lived.
  - A coordinated positive campaign to end the stigma of dementia led by the testimonies of people living with dementia
  - Intergenerational projects across schools and communities to 'normalise' dementia.
- **Proper inclusion of people living with dementia** in designing and delivering of ALL dementia learning and development for the whole health and social care workforce across York.

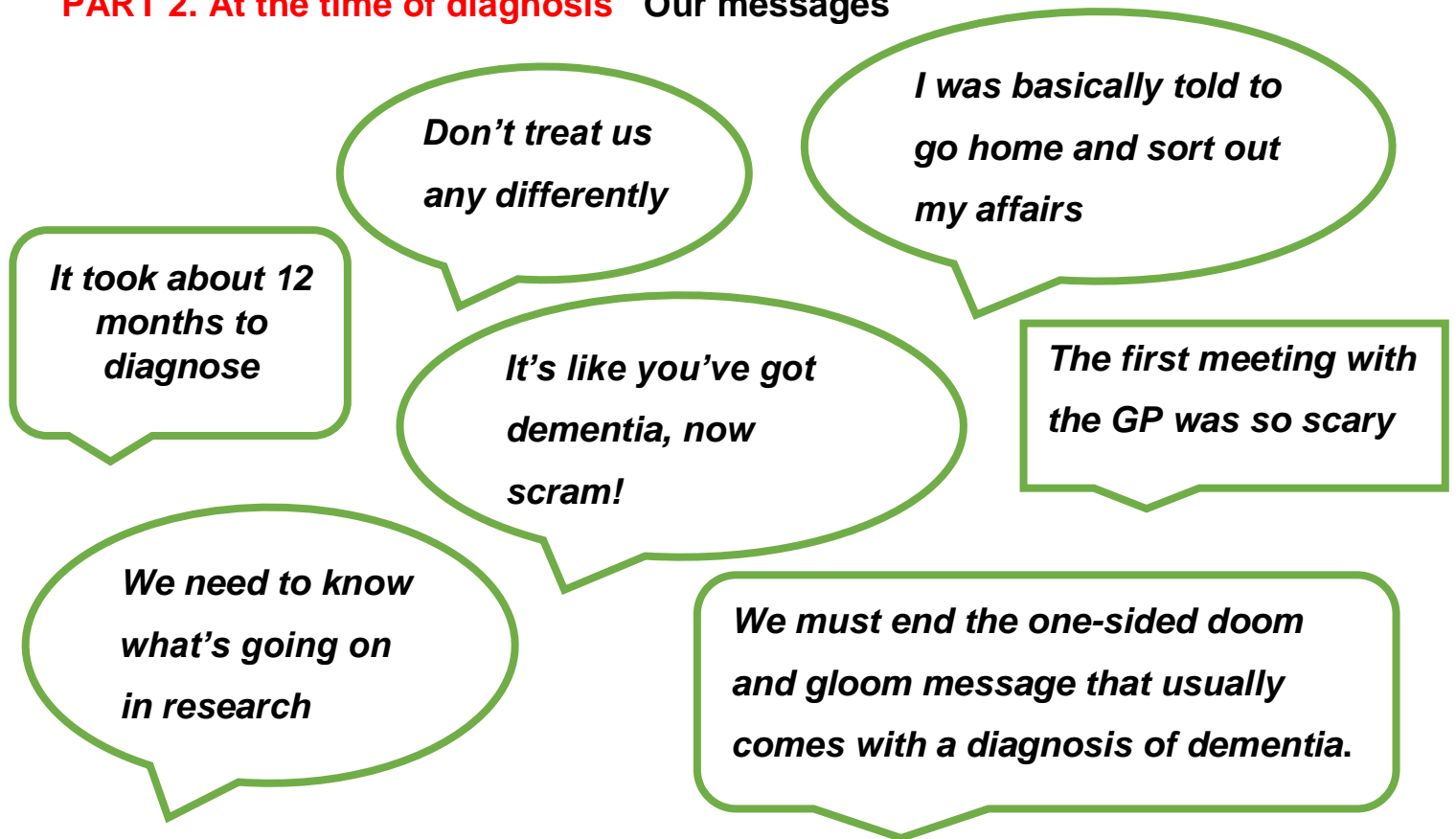
## Over to you!

These solutions ARE achievable.

To make YOUR service or work fit OUR needs, let's plan TOGETHER how to make them a reality.

We have LOTS of ideas and REAL examples of what we and others have already done to help you put the meat on the bones of these solutions.

## **PART 2. At the time of diagnosis** Our messages



### **Two Real Stories:**

#### **ELAINE:**

***I don't want to feel like a burden.***

We should not to be blamed for our dementia. We need help to get along better within close relationships. It causes stress for both partners

#### **WENDY:**

***Imagine yourselves being given a diagnosis of Young onset dementia.***

Your life falls apart. Services are non-existent so you feel abandoned.

Now, imagine the impact on your well-being, if someone came along and asked you to be involved in gathering information acknowledging that you still had a valuable opinion and views that mattered

That's what happened to me when I started to be involved in research.

Being involved has given me back that sense of purpose that a diagnosis of dementia stripped away from me.

Research gives me hope that my daughters will have a better future.

## Solutions

- **A personalised diagnosis – age and stage appropriate.**
- Acknowledgment from clinicians that medical information is only a small part of the bigger picture.
- **Positive language from clinicians and hope through research**
- Support to adjust to the change in our relationships eg Getting Along
- **Support from workers at our GP practice who can help with a smooth link to social activities locally.  
(known as Social Prescribing)**
- Everyone to be offered repeated opportunities to sign up to Join Dementia Research
- **Research not to be ON us but WITH us and BY us**

## Over to you!

As mentioned these solutions are ALL achievable. A good start is to watch our work film on the value of a sensitive and supportive diagnosis



Minds and Voices - the benefits of a supportive diagnosis

<https://www.youtube.com/watch?v=0suQyAR6lpg>

### **PART 3. Post diagnosis** Our messages

***We want Family Support  
– everything must be  
two way.***

***Services have to  
fit us rather than  
us having to fit  
into services.***

***We have so many  
unanswered questions  
about OUR own dementia***

***We need practical help to overcome  
barriers, caused by the environment and  
the values and attitudes of others***

#### **Two Real Stories:**

##### **GEORGE:**

***It's what I want that matters to me.*** Not what you think I might want or need. Ask me. Find out about my life. Ask my friends and my family what I enjoy. Don't think you can ever know better than me what I enjoy and what I need. Do NOT sit me in a circle in a church hall, facing people I don't know, singing a song I don't like, or doing a bloody word search. Unless I actually want to do that. And I don't.

##### **IRENE:**

When I was diagnosed ***I read all the books I could but then threw them away as they only increased my fear.***

It was MY dementia that I needed to understand. What better way than to do that with people who'd been through the same as me. The Good Life course is led by local people with dementia. It is a safe space to learn amongst equals. I'm in charge of my journey now – through being magnificent!

**Irene, George and many others will not follow pathways and roadmaps created by others. A strategy needs to support each person to forge their own path**

## Solutions

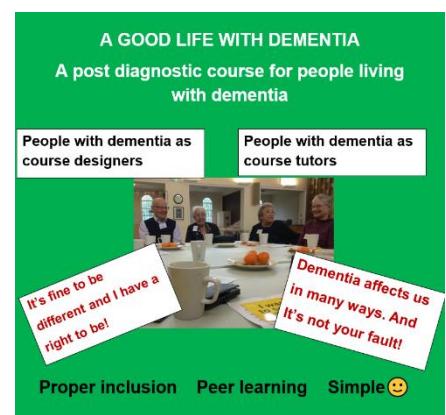
- Post diagnostic support should be **continually available**, as and when we need it.
- **Opportunities to join peer groups of people with dementia across the York area**
- Reference to 'Family' support instead of 'Carer' support - it's a two-way thing.
- **Provision of Getting Along programmes to support couples and families to adjust to the presence of dementia in their lives**
- Peer led and peer created post diagnostic support and information.
- **Services centred around us like a menu. Ones that fit our needs rather than what others think we want.**
- Improved way-finding and signage across public spaces and buildings
- **Printed materials aren't always what's needed but if published should be clearly written, simple and accessible**

## Over to you!

As mentioned above, all these proposed solutions are completely achievable!

For a starter, have a closer look at the post diagnostic course A Good Life With Dementia, first created by York Minds and Voices here:

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



## **PART 4. The Future** Our messages

*There's **STILL** a  
**LIFE** to be **LIVED**  
with it.*

*We should not be 'closed  
cases'. My GP never contacts  
me about how I'm doing with  
my dementia.*

*You've  
got to get  
involved!*

*We **ALL** have  
something to offer  
and a right to  
recover confidence*

*We can **LEAD**  
research and  
help develop  
services*

*We are not, nor should  
we be, passive recipients  
of care and services.*

### **Two Real Stories:**

#### **BARBARA:**

I went to a group of people diagnosed like me. ***I left. It was boring.***

The organisers were trying to put things on for us like word games, or activities. It was not developing or growing.

They were all very nice but we were a group of people with shared experiences and we could not own the group.

We all need a space to talk and share and discuss and act upon issues that arise and to contribute.

#### **BRIAN:**

After a recent hospital admission and serious illness, Brian and his family constantly had to challenge the 'Well he has dementia' approach.

Putting everything down to the dementia is dangerous.

It was not because of his dementia that he was ill.

Serious conditions such as Delirium - a medical emergency – could be missed.

Thankfully, as Brian says, ***'I'm still here!'***

**Barbara, Brian and so many more people with dementia have a right to grow, to learn and to live – not to be 'done to' or written off as already dead.**



## Solutions

- Once discharged from the specialists, we are 'handed back' to our GP. They should be more PROACTIVE in checking up.
- **Support should be continually available, as and when we need it, not as a time-limited offer.**
- Consultation with and inclusion of people with dementia on an ongoing basis, not as a tokenistic exercise
- **Build a sustainable network of peer-led groups across the York area.**
- People with dementia setting the local research agenda across the York region. Dementia Enquirers a prime example.
- **Awareness raising around the rights of people with a dementia to receive equal access to appropriate health care**

## Over to you!

As we have mentioned throughout, all our solutions are DOABLE.

We have many examples of what can be put into practice.

This strategy was not just been developed in November 2020, but rather after years of sharing as peers, and tapping into a wider UK network of peers with dementia, whose experiences mirror our own.

We want this strategy to serve as a set of clear guidelines to help YOU (whatever your role) to provide real practical support for people living with dementia and their families across York.

Because, as we said in our opening:

***'What is good for people with dementia is good for everybody'.***

York Minds and Voices. January 2021