George Rook

Living as well as I can
with Dementia

Um, where am I?

Be present when diagnosing

DAA

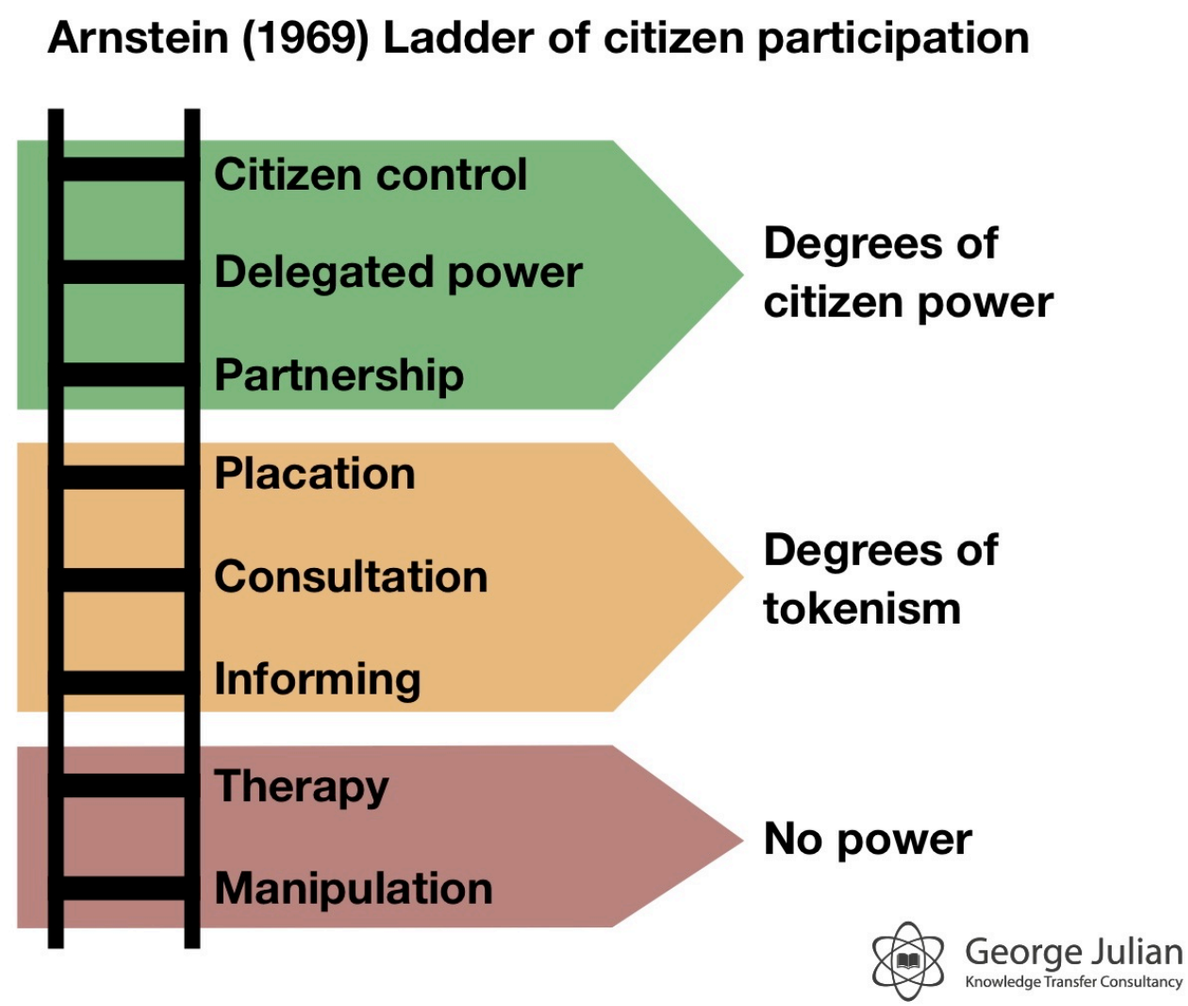
Shropshire Dementia
Action Alliance

Do we really want all this at once?

ideas
Vision
TO DO
Innovation

Levels of participation

- **Devolving**
- **Collaborating**
- **Involving**
- **Consulting**
- **Informing**



NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL

Risk of people developing dementia is minimised

"I was given information about reducing my personal risk of getting dementia"

STANDARDS:

- Prevention[1]
- Risk Reduction[5]
- Health Information[4]
- Supporting research[5]

DIAGNOSING WELL

Timely accurate diagnosis, care plan, and review within first year

"I was diagnosed in a timely way"

"I am able to make decisions and know what to do to help myself and who else can help"

STANDARDS:

- Diagnosis[1][5]
- Memory Assessment[1][2]
- Concerns Discussed[3]
- Investigation [4]
- Provide Information[4]
- Integrated & Advanced Care Planning [1][2][3][5]

SUPPORTING WELL

Access to safe high quality health & social care for people with dementia and carers

"I am treated with dignity & respect"

"I get treatment and support, which are best for my dementia and my life"

STANDARDS:

- Choice[2][3][4], BPSD[6][2]
- Liaison[2], Advocates[3]
- Housing [3]
- Hospital Treatments[4]
- Technology[5]
- Health & Social Services [5]
- Hard to Reach Groups[3][5]

LIVING WELL

People with dementia can live normally in safe and accepting communities

"I know that those around me and looking after me are supported"

"I feel included as part of society"

STANDARDS:

- Integrated Services[1][3][5]
- Supporting Carers[2][4][5]
- Carers Respite[2],
- Co-ordinated Care[1][5]
- Promote independence[1][4]
- Relationships[3], Leisure[3]
- Safe Communities[3][5]

DYING WELL

People living with dementia die with dignity in the place of their choosing

"I am confident my end of life wishes will be respected"

"I can expect a good death"

STANDARDS:

- Palliative care and pain[1][2]
- End of Life[4]
- Preferred Place of Death[5]

References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.

RESEARCHING WELL

- Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change.
- Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries.

INTEGRATING WELL

- Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer's Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care.

COMMISSIONING WELL

- Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice.
- Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources.

TRAINING WELL

- Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community.
- Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes.

MONITORING WELL

- Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each.
- Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation.

Risk?
What risk?

Dementia model for Shropshire, Telford and Wrekin

Living Well

My life a full life

Seven Elements

1 Remaining engaged within the community

- Dementia Action Alliances
- Activity groups that are dementia friendly
- Transport that us dementia friendly
- Information about community activities and support
- Dementia Advisers for all who choose, from start to end
- 6 monthly phone contact with all PWDs from Dem Adviser
- Social prescribing by primary care supported by voluntary sector
- Online chat room
- Reduce stigma and lack of understanding

2 Having a plan and preparing for the future

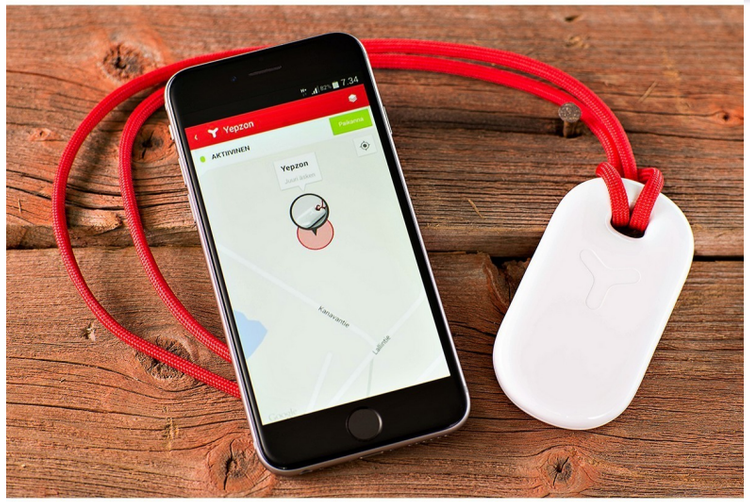
- Shared, co-produced living plan, held electronically and shared by PWD as they choose
- All PWDs enabled to plan DNAR, advance directives, etc
- Smart phone apps promoted for PWDs, with support
- IT systems in H&SC which allow easy sharing of info and living plans

3 Being connected with resources, knowledge and continued learning

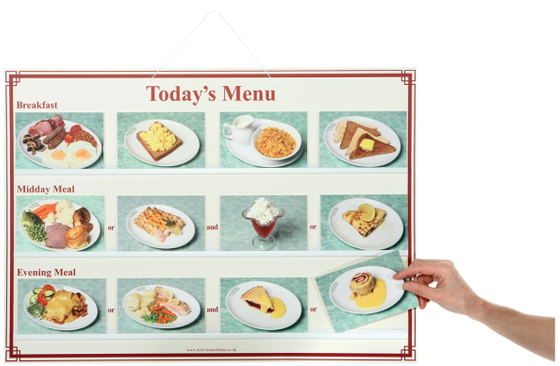
- PWDs encouraged to continue to join learning opportunities and research projects
- Information about these opportunities easily accessible and held in one place far as possible
- PWDs provided with support and training for use of ipads and tablets
- Information and course details should be in dementia friendly, accessible form
- Providers of learning and research opportunities should be encouraged to me their local DAA

4 Using assistive technologies

- Easily accessible catalogue/s of available assistive technology (AT) available online and on paper
- All health and care professionals should be made aware of these devices and aids and should use every contact with PWDs and carers to promote use
- An organisation should be commissioned to lead on use and promotion of AT
- Dementia advisers should make sure all PWDs and carers are provided with or have access to details of AT available



5 Accessing individualised, dementia friendly care and support as and when needed



- All commissioned providers of health or care services should be dementia friendly, and members of the local DAA
- Staff in commissioned H&C services should all receive dementia care and awareness training
- Contractual levers should be used to achieve this
- The Roadmap should only list dementia friendly providers of health and care services

6 Support for Carers

- Carers should be provided with support, information and time away when they want it, to avoid crisis
- Telephone support service for carers, including 6 monthly calls to all, with referral to dementia advisers and carer organisations when necessary
- GP practices should identify and list all carers, and train staff to recognise carer stress and make every contact count
- Social prescribing by primary care professionals should be given to carers as well as PWDs
- Carer assessments should be easily accessible via single point of access. Barriers should be minimised
- Respite opportunities in many forms should be provided for carers when they feel the need, and before crisis, and carers should be frequently reminded of these and supports to access them

7 Peer groups

- Should be run by peers for peers, with facilitation support
- Training, coordination and admin support should be commissioned to enable peer groups to happen
- There should be peer groups for PWDs and/or carers, within local communities and within age or interest groups, to suit all

Social Movement to Influence Change

"Never doubt that a small group of thoughtful committed citizens can change the world - indeed it is the only thing that ever does"

Margaret Meade

What is a social movement?

Social movements are a type of group action. They [may be] large, sometimes informal, groupings of individuals or organizations which focus on specific political or social issues. In other words, they carry out, resist, or undo a social change.
- Wikipedia

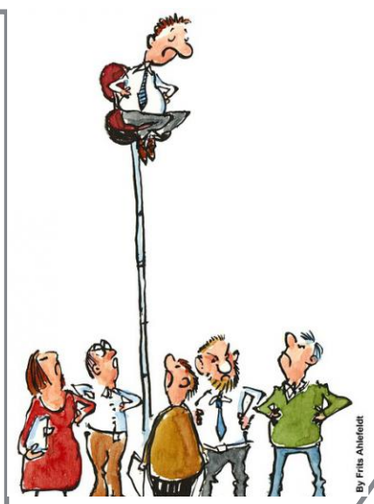
Shropshire Telford and Wrekin Dementia Action Alliance
Dementia friends
Animal rights
No pylons in mid Wales

"...social movement thinking is about connecting with peoples' core values and motivations and mobilising their own internal energies and drivers for change."

Helen Bevan

A social movement is NOT...

Controlling



Hierarchical

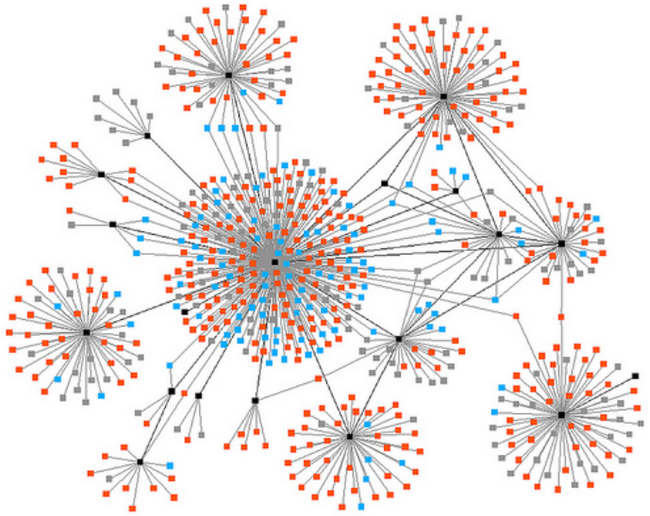
Dictatorial

Not even "democratic"

How do we get influence?

90% of influence comes from personal networks and contacts

Not from formal or unsolicited invitations



Don't waste your time or passion

Surround yourself with people who share your values and trust you

Avoid people who are negative and drain your energy

Why do you think there is so little real co-production in the NHS?

The usual responses...

I've heard all these

But they'll ask for the impossible!

It'll take too long... I haven't got time

Patients don't understand...

How can one person represent everyone else?

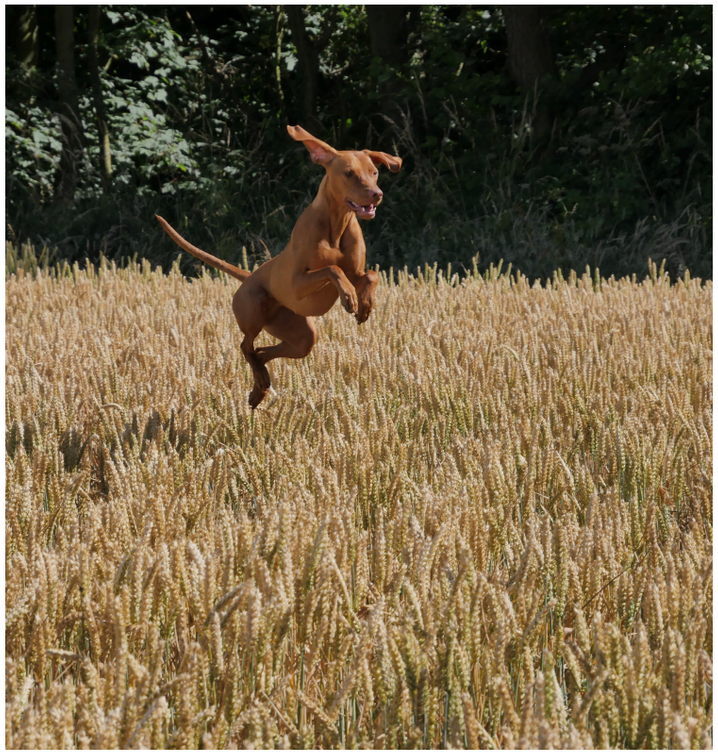
What a palaver...I can do this in two weeks on my own

But we'll ask patients what they think at the end

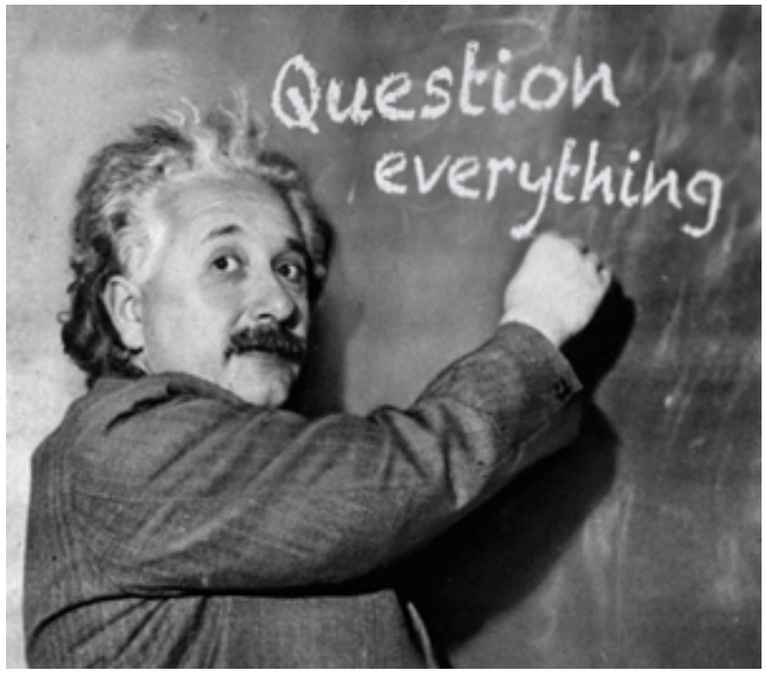
We'll lose control!

Michael Ignatieff once said:

"There are few presumptions in human relations more dangerous than the idea that one knows what another human being needs better than they do themselves."



Go forth and...

Disrupt

Any questions?