

# Welcome to today's webinar

- Now that you have joined, you will notice that you are on mute.
- It will stay on this slide and you will not hear anything until approximately 14:05pm.
- If you have any questions throughout the webinar, please write them in the Private Chat section located in the below right panel.
- There will be an opportunity to have your questions answered at the end in Q&A.
- This webinar will be put on the DAA website afterwards (with no audio).
- Make sure you have dialled 0800 783 6753 and entered 63021108#

# How the Dementia Statements can bring about improvements

## Moving from rhetoric to reality!

**Jean Tottie**

**Chair of LSN & tide, Carer Representative on the National DAA Steering  
Group**

# Dementia Statements Review Process

- **Sept 2016 - Steering group**
- **Oct 2016 – Feb 2017**
  - **Groups and interviews**
  - **A survey of organisations**
  - **Context/Literature review**
  - **Information from State of the Nation**
- **March 2017 - Drafting workshop** by people living with dementia and carers
- **April 2017 – Consensus building workshop** including key organisations and people living with dementia and carers
- **April 2017 – New Statements presented to the Dementia Programme Board - accepted**

# Dementia 'We' Statements

- We have the **right** to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.
- We have the **right** to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.
- We have the **right** to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.
- We have the **right** to be respected, and recognised as **partners in care**, provided with education, support, services, and training which enables us to plan and make decisions about the future
- We have the **right** to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

# Dementia, rights, relationships and power dynamics

- There is more that connects us than separates us – **rights** are about us as individuals and about **basic humanity**
- This process enabled **people living with dementia and their carers the opportunity to determine what is important to them**
- Most of the Dementia Statements are about how we **develop effective and equal relationships** with each other as human beings
- They reflect the need to **shift the balance of power** from professionals / care providers/ commissioners to **individuals with dementia and their carers**
  
- **Putting human rights into practice will only be achieved when we consciously and deliberately put individuals and their carers at the centre**

# How the Dementia Statements can bring about improvements

- **Enable** people living with dementia and carers to be more aware of their rights and recognise when they are at risk of being breached
- **Empower** people living with dementia and carers to exercise their rights and begin to shift the balance of power and accountability back to them
- **Assist** in the shift from a dominant medical model of care to a more social model of disability – changing the prevailing discourse around dementia
- **Provide** frontline staff with a new ‘lens’ through which to see situations and ensure that the persons rights are promoted, respected and upheld;
- **Enable** CQC to regulate and audit quality of care against an explicit rights agenda
- **Provide** a rights based framework, for both commissioners and providers, against which to undertake an impact assessment for any plans / changes in the provision of care and support

# Risk of Complacency

*“Human rights complacency happens when **stakeholders delude** themselves into thinking that the articulation of rights **is equivalent** to the realisation of those rights.*”

*Merely having excellent human rights based legislation **does not give the citizen the ability** to realise and access those self-same human rights.”*

Donald McCaskill – CEO Scottish Care  
Launching a Human Rights Fund in Scotland  
29<sup>th</sup> Nov 2017

# Are we at risk of resting on our laurels?

- Ambitions and aspirations of being a 'Global Leader' in the field of Dementia & presentations to international conferences
- UK Global Dementia Ambassador

Etc .....

- **But.....**
- What do we really know about the lived experiences of people living with dementia and their carers everyday?
- What are the results of the first Citizens Panel Report - what will happen to this valuable information?



“For the past few years much has been written, and even more said, about ‘**person-centred care**’, ‘**living well with dementia**’ and ‘**dementia friendly communities**’.

This is almost **meaningless without greater emphasis and attention being paid to the human rights** of those affected by dementia [including] our ... partners, family and close friends, each of whom shares the caring role and the impact of the dementia.” (Keith Oliver)

## Our Lived Experience

### Current Evidence on Dementia Rights in the UK

An Alternative Report to the UNCRPD Committee



Co-produced by  
The Dementia Policy Think Tank  
The DEEP Network  
Innovations in Dementia CIC

26 July 2017



**tide**<sup>™</sup>  
together in dementia everyday

“As a carer for my mum one thing I feel that has been missing from day one is **the right to know what we are entitled to**. We have only accessed and benefited from certain things due to our own determination to gain access to help that we deserve. **We should be made aware of what is out there, it shouldn't be a hidden secret.**”

**Natasha Hamilton**

Carer

[www.butalzheimersisforoldpeople.co.uk](http://www.butalzheimersisforoldpeople.co.uk)

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2017



**Ray Fallan**

Carer

“My rights as a carer are as equally as important as my right to care for a loved one. Caring for someone can be all consuming. Before you know it, you lose contact with people that have been important in your life”

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# Closing the gap & moving rights from rhetoric to reality - much more work required.....

The Dementia Statements need to be mapped across to the following:

- Human Rights Act 1998
- UN Convention on the Rights of People with disabilities - dementia now recognised as a disability as from August 2016
- Equalities Act 2010 – requirement to make reasonable adjustments
- CQC – Inspection and regulation - resource Equally Outstanding 2017
- Care Act 2014



# What we need to ensure the Dementia Statements can truly bring improvements

- Specific resources to enable those living with dementia and their carers to help them understand the meaning and relevance of the rights and thus to exercise them
- A series of resources to enable those tens of thousands of front line workers in health, social care and housing, who will be responsible for putting them into practice
- **Political & policy level leadership** and commitment to provide the relevant resources to train, equip, build the understanding and confidence of the workforce?
- Above all we need **you** members of DAA to commit to implementing the new Dementia Statements of the Declaration

# Thank You!

Jean Tottie – Chair of LSN & tide  
jean@lifestorynetwork.org.uk

Tide – <http://tide.uk.net/>

# Wendy Wells

## Head of Policy and Business Implementation

Guinness Care

- Why are the Dementia Statements important to your organisation?
- How did you go about filling in your revised DAA Action Plan?
- Why should other National DAA members fill in the updated Action Plan?

# Emily Cook

**Public Affairs Advisor**  
Alzheimer's Research UK

- Why are the Dementia Statements important to your organisation?
- How did you go about filling in your revised DAA Action Plan?
- Why should other National DAA members fill in the updated Action Plan?

# Thank you

We hope that you enjoyed today's webinar. These are open to everyone, so please forward on the details for future webinars.

\*Questions, please email [ndaa@alzheimers.org.uk](mailto:ndaa@alzheimers.org.uk)

\*Dementia Statements [www.dementiaaction.org.uk/nationaldementiadeclaration](http://www.dementiaaction.org.uk/nationaldementiadeclaration)

\*Slides / past webinars visit [ww.dementiaaction.org.uk](http://ww.dementiaaction.org.uk)

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