

Partners in Care – shifting the balance of power! Making it a reality.

Dementia Action Alliance

Devolution : what it means for you

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Life Story Network / Tide

What I'm Going to Talk About.....

- Why focus on carers & their diverse needs?
- Using Dementia United as the litmus test for carers as leaders & partners in Care with **tide**
- **tide** – together in dementia everyday
- Time for fundamental change – from rhetoric to reality!
- Questions can be picked up in the panel session

Why Focus on Family Carers of People with Dementia?

- 850,000 people living with dementia in the UK and 700,000 friends and family are caring for a person with dementia (Alzheimers Research 2015).
- They're the biggest workforce in dementia care – providing 44% of the total cost of care.
- They save the public purse about £11b per year.
- They face particular difficulties due to the complex, unpredictable and progressive nature of the illness.
- 69% reported that caring had a negative impact on their physical health.



Diverse Needs of Carers - BAME

- At times we talk about ‘Hard to Reach Communities’ or should we reframe to ‘**Easy to Ignore Communities.**’
- BAME refers to “all people of minority ethnic status in England. It does not only refer to the skin colour but to people of all groups who may experience discrimination and disadvantage, such as those of Irish origin, those of Mediterranean origin and Eastern European origin.” (DH 2005)
- 25,000 people currently living with dementia from BAME communities, rising to 50,000 by 2026 and 172,000 by 2051 (Fontaine et al 2016).
- Early onset dementia and vascular dementia most prevalent in these communities associated with hypertension and diabetes.
- Important to challenge assumptions -‘They look after their own, don’t they’ report in 1998 – challenged myths around caring as part of an extended family.
- Carers from BAME communities currently underrepresented in dementia services (Moriarty et al 2011).
- Potential for Asian women to feel ‘trapped and powerless due to norms about gendered roles in their communities’ (Mand 2006).



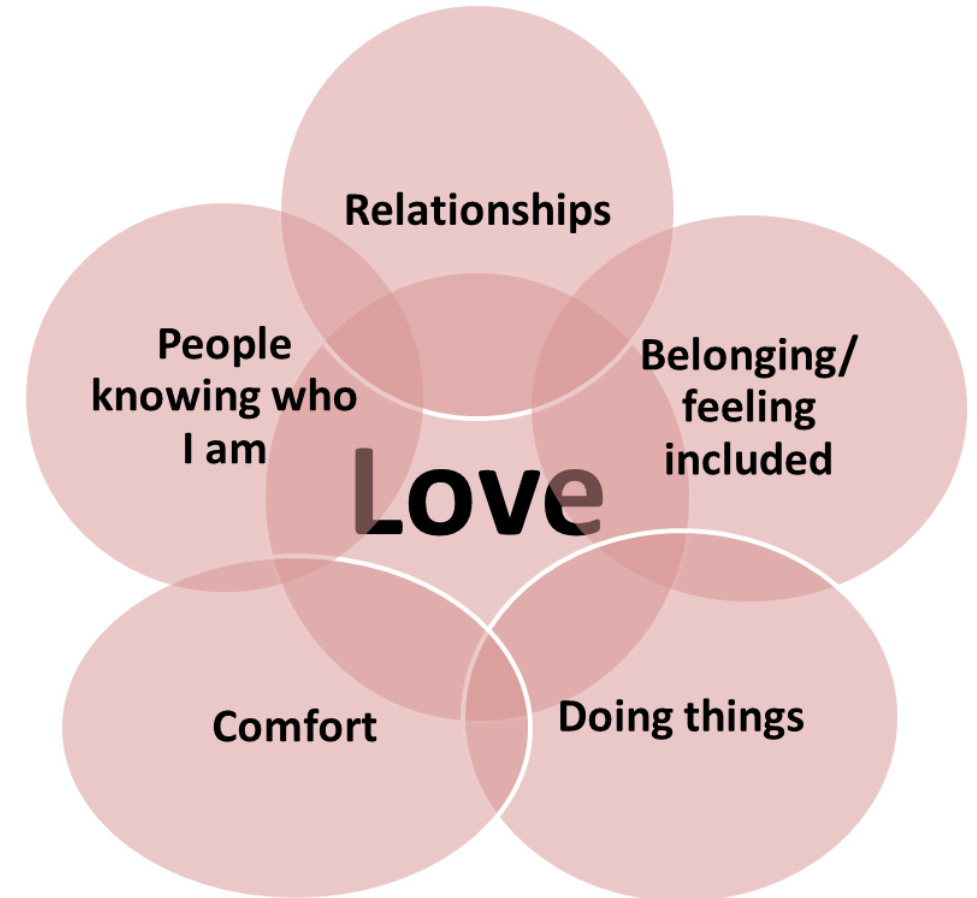
I didn't come out to go back in the closet!- LGBT

- Estimated that LGBT community is between 7.5% and 10% of the total population (Aspinall 2009).
- Estimated for Trans people in UK vary widely from 65,000 to 300,000 (ONS 2009).
- Lack of focus on the needs of LGBT and Trans people caring for people with dementia **is a reflection on lack of research** not lack of need!
- Needs of LGBT carers of people living with dementia need support, love, respect and dignity & **their voices heard**.
- Lightly to **experience stigma, discrimination and marginalisation** with many having vivid memories of pre-stonewall, when compelled to conceal their sexuality (issues of psychological and emotional distress).
- Both carer and person living with dementia who are in an LGBT relationship suffer '**triple jeopardy**' – LGBT identify, cognitive impairment and ageing (McGovern 2014).

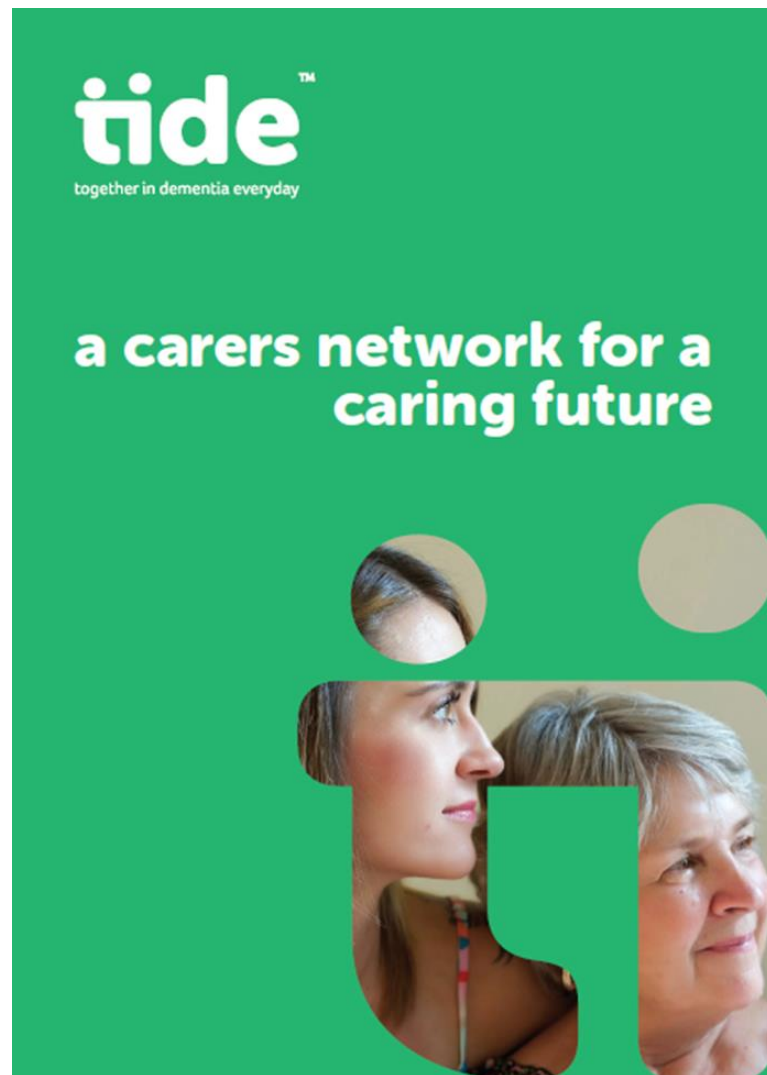


Reflecting the aims of Dementia United are to:

- **Improve the lived experience** of people with dementia and their carers
- Reduce pressure on the health and social care system
- **Pledge 4 - To co-produce and redesign**
- What do you need to be well and happy?



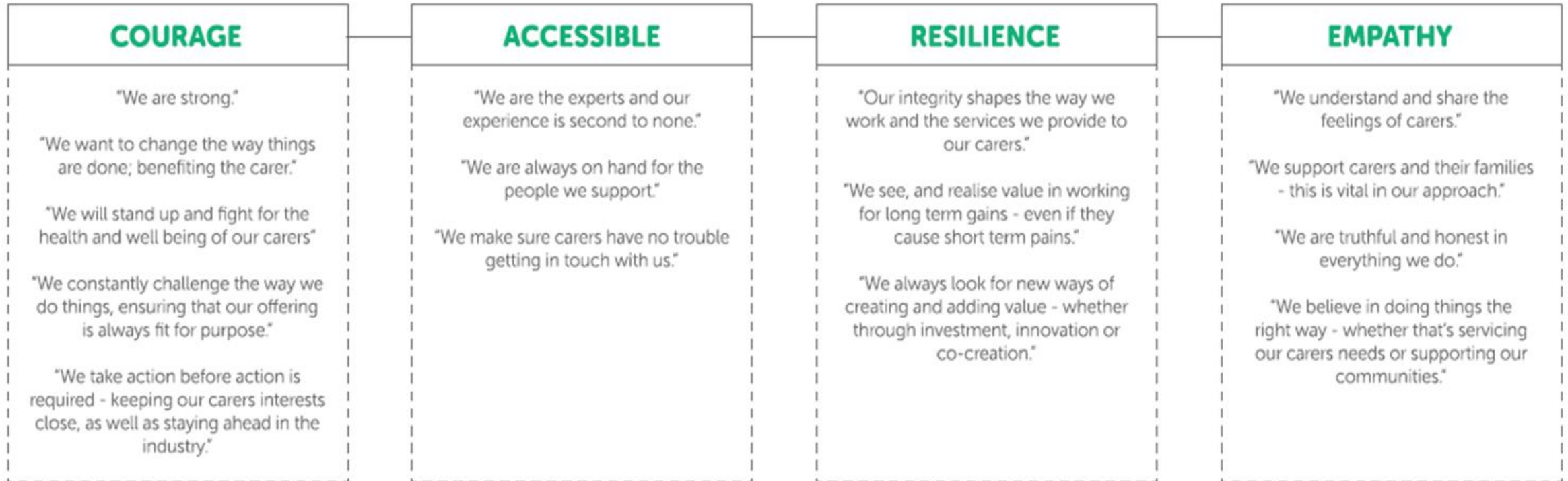
Using Dementia United as the litmus test for carers as partners in care with



Increasing Level of Community Involvement, Impact, Trust and Communication Flow

Outreach	Consult	Involve	Collaborate	Shared Leadership
Some community involvement	More community involvement	Better community involvement	Community involvement	Shared leadership & mutual respect (recognising expertise of both)
Communication flows from one to the other to inform	Communication flows to the community and then back – answer seeking	Communication flows both ways;- participatory form of communication	Communication flow is bi-directional	Strong bi-directional relationships
Provides community with information	Gets information and feedback from the community	Involves more participation with the community on issues	Forms partnerships with the community on each element of the project from development to solution	Final decision making at community and neighbourhood level
	Entities share information	Entities cooperate with each other	Entities form bi-directional communication channels	Entities have formed strong and robust partnership structures and processes
Outcome: <i>Establishes communication channels for outreach</i>	Outcome: <i>Develops connection</i>	Outcome: <i>Visibility of partnership establishes with increased cooperation</i>	Outcome: <i>Partnership building and trust building</i>	Outcome: <i>Broader health outcomes affecting broader communities; Strong bi-directional trust built Mutual respect & shared leadership</i>

The Vision and Mission of **tide**



Tide's Mission

Our mission is to:

- Provide carers with the **tools and support to help themselves** and others
- **Challenge** perceptions of carers of people with dementia in society
- **Campaign** for better carer support
- **Influence** Government legislation and policy
- **Speak on behalf of people** who can't speak out for themselves
- **Educate** people, organisations and society on the importance of carers
- **Connect carers** with other carers – developing a truly unique network

Impact and Outcomes

Through our co-produced development programme for carers of people with dementia we want to have the following **impact**:

- Promote a **social model of dementia**, where we as carers are seen as citizens in our own right and have our needs anticipated, identified and met;
- Ensure that we **adopt a rights based approach**, based on what is important and matters to people, who need access to care and support
- Be respected and valued as experts and **partners in care**
- Ensure carers are fully involved as **leaders** at local, regional and national levels in **shaping the commissioning, re-design and delivery of care and support**, that is meaningful to individuals and their carers
- **Hold the local systems (partners) to account** to ensure that people live well with dementia

Through this approach we will bring about radical change and achieve the following **outcomes:**

- Care and support for the person we are caring for and which is based on **continuous mutually respectful relationships** with the care providers / professionals
- Care and support is **customised to what is important to us** as individuals taking account of our values, beliefs and culture;
- We and the person we are caring for **remain fully in control of any decisions about the care and support needed**
- **Knowledge and information is shared and flows freely** between the care providers / professional and us to enable us make informed decisions in a timely manner
- **All decisions are based on best practice and evidence** not driven by pressures (financial or system capacity)
- **Safety is everyone's responsibility**, but balanced with appropriate calculated agreed risk (avoid being risk averse)
- **Open, honest and transparent communication** at all times

Time for fundamental change – from rhetoric to reality!

“The health and care system will be fit for the future when patients [**people**] and service users **will be actively involved in designing care, are seen as key members of the care team, given adequate information and support to self – care and manage their condition**” (Ham 2012)

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