Short term and long term planning: Providing the right support to people with complex needs and a diagnosis of dementia

Dr Fiona Pipon-Young, Consultant Clinical Psychologist, St Peter's Hospital

LUDLOW STREET HEALTHCARE

www.lshealthcare.co.uk

Overview

- Current policy context
- Case example from St Peter's: Edward
- Current ongoing challenges
- Where next?

Dementia

- Dementia is caused by diseases of the brain and has symptoms which include the gradual loss of memory, reasoning and communication skills
- There are many different types of dementia, with the most common being Alzheimer's Disease and vascular dementia
- Dementia is not a natural stage in the ageing process but a progressive illness that tends to affect the individual in a gradual manner, moving from initial memory problems to the loss of the essential elements of mental functioning
- There are approximately 37, 000 people diagnosed with dementia in Wales
- With an ageing population, this number is set to increase by around a third by 2021
- Dementia is a major concern for health and social care services
- It is the single most frequent cause of admission to care homes, and the need for community care services for older people.

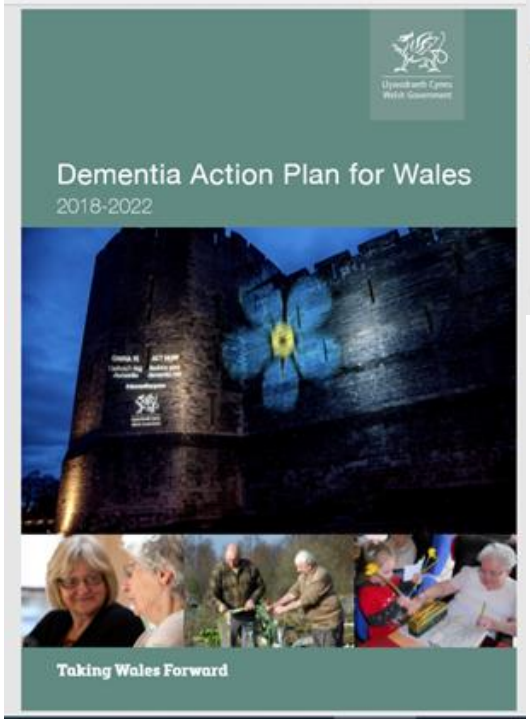
Where are people with dementia treated?

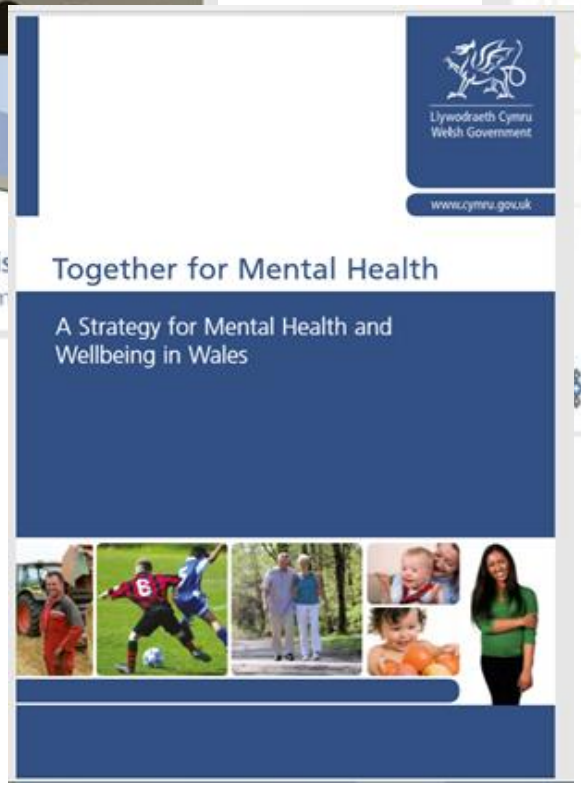
- Majority of people with dementia live at home
- Nearly 2/5 live in care homes
- It has been reported that provision of specialist care home places may be worse in Wales than in England, with Wales having just 14 dedicated care home places per 1,000 of the population aged 75 and over, compared with 20 or more in most other UK regions.
- There is wide variation across Wales in NHS provision for people with dementia. Most areas will have acute in-patient assessment beds; some have day hospital provision, for assessment and treatment; some have continuing assessment beds, where length of stay may be extended and end-of-life care provided (Improving Dementia Care, 2010)


GIG CYMRU NHS WALES
Matrics Cymru
Guidance for Delivering Evidence-Ba
Psychological Therapy in Wales
Written by the National Psychological Therapies Management Committee, supported
September 2017


Alzheimer's Society
Leading the fight against dementia
www.cymru.gov.uk
National Dementia Vis
Dementia Supportive Com


How to Guide
15
1000 LIVES O FYWYDAU
Improving Dementia Care

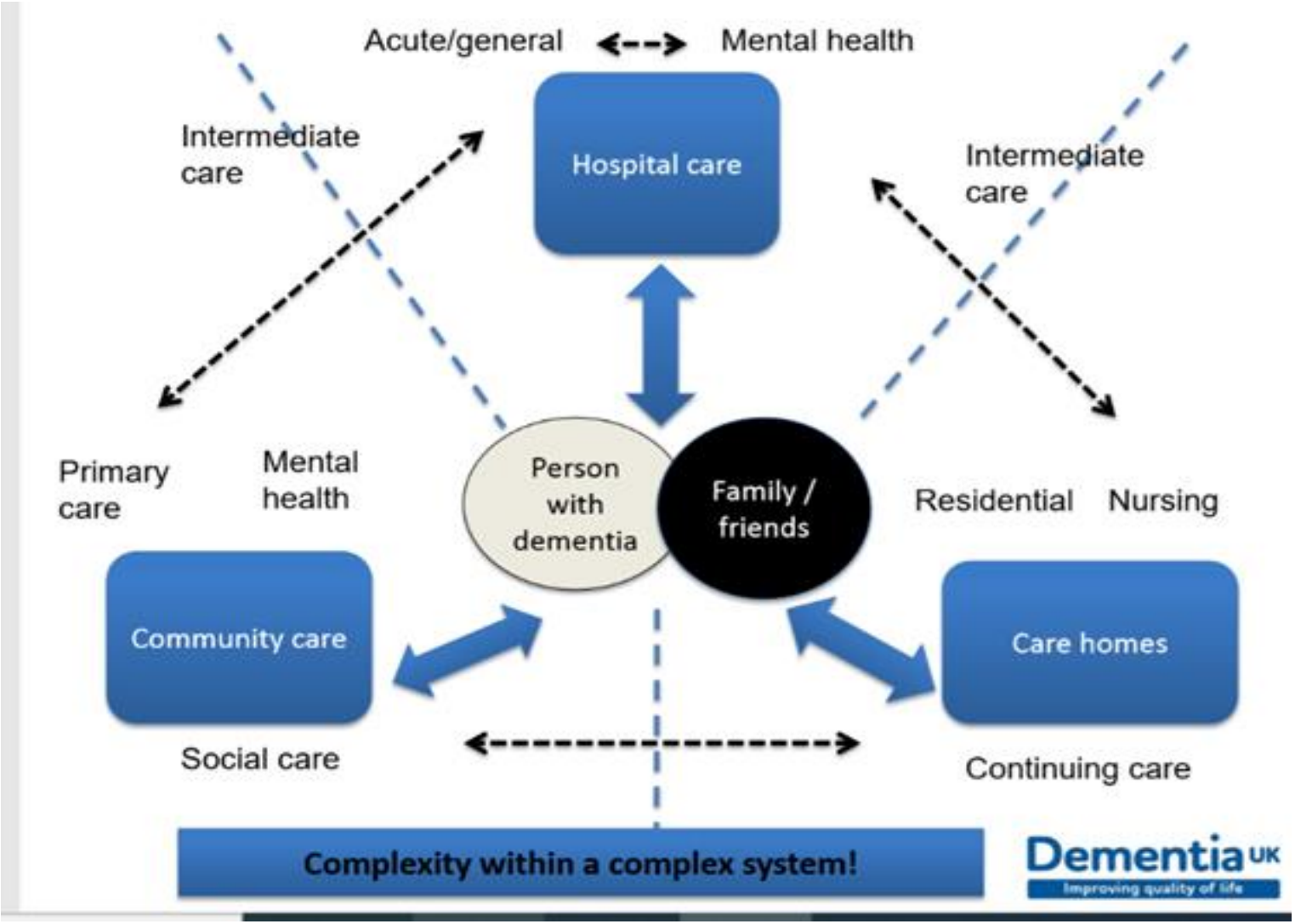

Dementia Action Plan for Wales
2018-2022
Taking Wales Forward


Llywodraeth Cymru
Welsh Government
www.cymru.gov.uk
Together for Mental Health
A Strategy for Mental Health and Wellbeing in Wales

Key messages…..

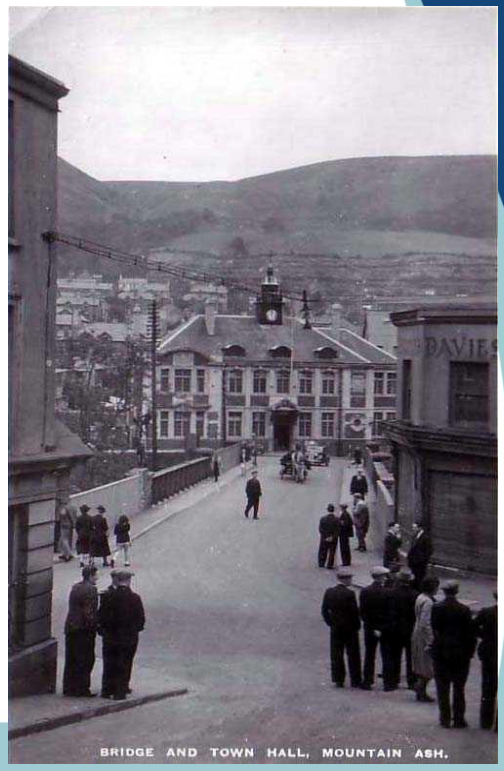
- To ensure that those who need treatment receive the right treatment at the right time and in the right place
- Priority to develop ***more closely integrated services, more comprehensive programmes of care and a greater understanding of the needs of people with dementia and their family and carers***
- ***1000 Lives Plus: Intelligent Targets for dementia:***

- ❑ T**arget 1**: Memory Assessment Services/First point of contact – reduce time between onset of symptoms & diagnosis being communicated
- ❑ **Target 2**: Improved quality of general hospital care for people with dementia and reduced length of stay
- ❑ **Target 3**: Reduced inappropriate use of anti-psychotic medications in accordance with NICE/SCIE guidelines - through good quality person centred care
- ❑ **Target 4:** Improved support for care givers
- ❑ **Target 5:** Improved quality of care in NHS dementia inpatient units – including access to psychologically informed interventions and working closely with family and friends


Acute/general
Mental health
Intermediate care
Hospital care
Intermediate care
Primary care
Mental health
Person with dementia
Family / friends
Residential
Nursing
Community care
Care homes
Social care
Continuing care
Complexity within a complex system!
Dementia UK
Improving quality of life

Getting the right treatment at the right time, with the right outcome

- Case example: Edward
- Edward grew up in Mountain Ash
- He had described a happy childhood – enjoying school and sport
- He passed his civil service exams after leaving school and worked as a civil servant throughout his career, retiring at the age of 65
- Edward completed his National Service during the 1950s and often described a number of traumatic experiences during this time
- Edward has two children, a wife and a brother



Case example: Edward

- Edward was diagnosed with Alzheimer's dementia in 2016 at the age of 75
- Edward was receiving support from secondary care mental health services due to 'aggressive outbursts'
- His relationship with his wife had broken down and his daughter has Lasting Power of Attorney
- He was placed in respite care, in order for his family to have a break
- Whilst there Edward assaulted another resident
- The assault was serious and Edward was moved to an acute inpatient dementia care ward
- Edward's presentation whilst in hospital was described as 'confused'. He was often disorientated to time and place
- Edward often believed he had just returned from military service and believed that other patients and residents were breaking in to his property – this was particularly so during the early evening (sun downing?). At these times he was likely to become verbally and physically aggressive towards others

Case Example: Edward

- Edward was transferred to St Peter's Hospital approximately 12 months ago
- Edward followed our 16 week assessment pathway.
- During this time a variety of information was sought including:
  - completion of behaviour monitoring charts
  - clinical formulation discussion with staff including:
    - reviewing Edward's history
    - Developing an understanding the triggers to his 'aggressive' behaviour
    - Reviewing medication
    - Occupational Therapy assessment/ intervention – Pool Activity Level (Functional Assessment); interests and occupation – tailored activities
    - Dietetics – specific guidelines in place to manage diabetes
    - Speech and Language Therapy – communication assessment profile (CASP) – guidelines and support for staff
    - Physiotherapy – Mobilising independently

Person centred formulation (based on Newcastle Model)

Personality

Normally happy, kind gentle man. Enjoys others' company, very sociable. Able to make choices in relation to food preferences and dressing

Physical Health

2007 Diabetes (management plan in place)

2016 Alzheimer's Disease

2019 Recurrent UTI

Medication

Epilim 500mg

Linagliptin 5mg

Lorazapam 1mg (as required)

Appearance and Emotions

Frightened

Upset / confused

Lost – can't find room

Anger

Life story

Grew up in Mountain Ash

Enjoyed school and was a keen sportsman

Married aged 25 with two grown-up children ; loving father although strict at times. Enjoys listening to 70s music and reading the paper; enjoys socializing with others , 'chatting'

Being 'well dressed'

Trigger

Confusion – believing others are intruders in his home (usually when he wakes at night and is disorientated to place)

Arguing/ raised voices (?PTSD)

Loud noises

Behaviour

Raising voice to others when they are loud/ shouting

Entering other clients' rooms

Shouting at others when they raise their voice

Attempting to hit others when Edward feels threatened

Needs:

Physical comfort – pain free

To feel safe

Occupation

Love and belonging

Contact with others – singing and chatting

Cognitive Abilities

Diagnosed with Alzheimer's in 2016

No insight or awareness into his difficulties, although does know he is struggling to find words

Disorientated to time and place

Is unable to recognize carers or friends and family

Pool Activity Level: Sensory

Receptive and expressive language difficulties

Social Environment

Edward spends his days in communal areas . He will often position himself next to other residents and attempt to engage them in conversation.

He enjoys music and singing with staff

Mental Health

No past mental health history

Query PTSD?

No signs of depression or anxiety

Vocalisations

Rhythmic speech, limited content

Repetitive words and blowing raspberries (particulatrly when the words don't come)

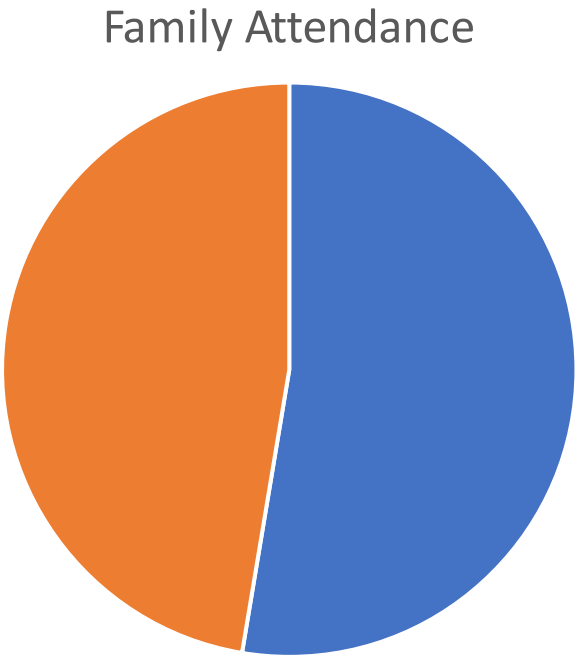
Person centred care

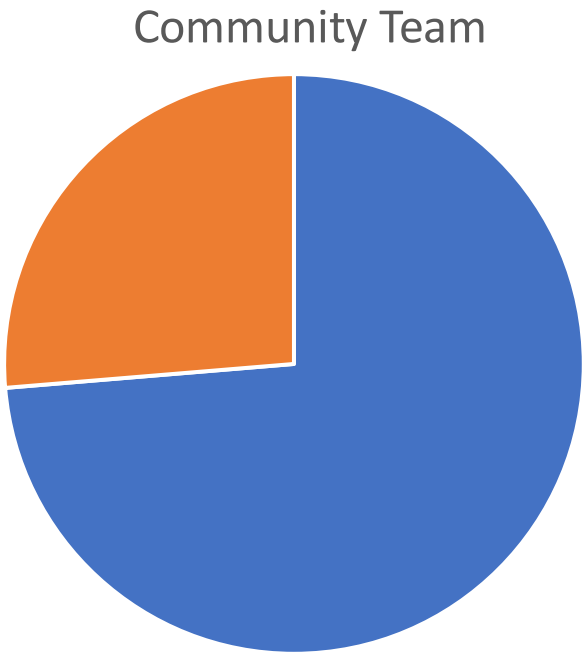
- Developing a person centred formulation helped to identify the triggers causing Edward's distress and more importantly reduced periods of distress, allowing staff to work with Edward
- Interventions were tailored to his needs including Life Story, animal assisted therapy (real and robotic); music therapy; validation techniques
- Edward also enjoys being with staff and feeling useful – given jobs to do…
- Edward's family have had limited involvement in his care. His wife no longer felt able to be involved and his grown up children live a reasonable distance away
- However, Edward's community mental health team have remained closely involved
- Does Edwards need to be with us still…… probably not
- "No suitable placements available close to his home"

Ongoing challenges…..

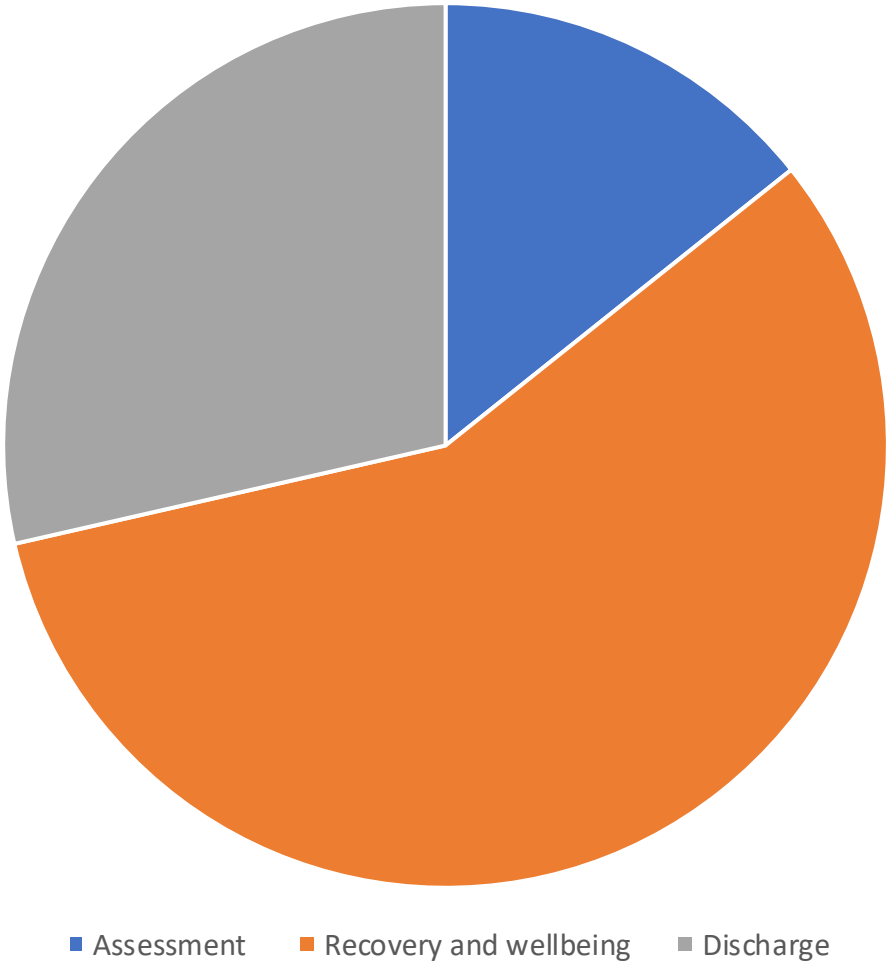
- Involving family can be difficult due to our service users often being far away from home
- Often families have been through a difficult time and had to cope with highly distressing situations
- **What we need to do:**
- Supporting families in finding support locally (e.g. Alzheimer's Society; Carers Wales); psychoeducation ('they don't know who I am anyway') and providing a welcoming environment for families is essential in supporting their ongoing connection with their loved ones, utilising technology (skype, FaceTime)
- Involving family in meetings – using technology, exploring why they come/ don't come, alternative ways of involving family
- Continued close relationships with our NHS community colleagues whilst also continuing to build on these - contact and communication formerly during CTP/ CPA meetings and day to day liaison
- Discharge discussion starting at admission

Current attendance at CTP/ CPA meetings (2018/2019)





Patients currently within our care pathway



Where next?

- We know people with dementia experience distress when they are communicating an unmet need to us
- We know good person centred care planning allows us to understand the person, understand their needs, how they communicate these and importantly how we may begin to support them
- This forms the ‘acute’ phase of assessment and treatment, followed by a period of treatment/ establishing stability. Following this people need long term support closer to home
- We know people are better off in residential and nursing home care rather than hospital settings
- We need to increase the numbers of nursing homes and care homes that can provide dementia friendly environments with staff who have been trained in dementia care – who also have access to high quality community support, consultation and expertise
- Finally, we need to ensure that dementia does not become a disease of isolation and that our communities are accepting of the difficulties and retained skills of people with dementia

References

NICE-SCIE (2006). Dementia: supporting people with dementia and their carers in health and social care: Clinical Guideline 42. London, National Institute for Health and Clinical Excellence.

James, I. A. & Jackson L. (2018). Understanding Behaviour in Dementia that Challenges. A Guide to Assessment and Treatment. London: Jessica Kingsley Publishers.